


SHORT REPORT

Caregiver appraisals of lucid episodes in people with late-stage Alzheimer's disease or related dementias

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Abstract

Introduction: Little is known about how family caregivers who witness unexpected and spontaneous communication among people in late stages of Alzheimer's disease and related dementias (ADRD) appraise these episodes of lucidity (EL).

Methods: In an electronic, cross-sectional survey for former and current caregivers who participate in UsAgainstAlzheimer's A-LIST[®], participants who reported witnessing an EL were asked how positive and stressful ELs were, if they made or changed decisions based on an EL, and what resources they sought out to explain ELs.

Results: Caregivers reported 72% of ELs to be quite a bit or very positive, 17% to be stressful, and 10% to be both stressful and positive. Twelve percent of caregivers changed care plans because of ELs and 13% sought out information about ELs.

Discussion: These exploratory data suggest caregiver reactions to EL vary. Caregivers may change or postpone care decisions due to EL, and few resources exist to address caregiver queries about EL.

KEYWORDS

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

1 | INTRODUCTION

People living with Alzheimer's disease and related dementias (ADRDs) require increasing amounts of care and support as their disease progresses. Family caregivers often assume responsibilities for relatives with ADRD, providing direct care, managing challenging behaviors, and ensuring safety.^{1,2} As their relatives' condition declines, caregivers experience analogous transitions, shifting from active engagement

in seeking information and help to cope with transitions in care, to perseverance in their role and resignation with the progressive cognitive decline, to grief and readjustment.³ Transition theory posits that lacking knowledge or self-efficacy about managing these transitions poses risks for individual well-being. To circumvent these risks, education and skill development is needed.^{4,5} Interventions to improve role transitions for caregivers of people with ADRD that are initiated early in the caregiving trajectory improve coping, self-efficacy,

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knowledge of available services, and preparation for future care needs for relatives.^{6,7}

1. **Systematic Review:** The authors reviewed literature using traditional (e.g., PubMed) sources. Research on episodes of lucidity (EL) is in the earliest stages. To date, most research has relied on case reports and cross-sectional study designs. Recent publications describe scientific and methodological challenges in studying EL. These relevant citations are appropriately cited.
2. **Interpretation:** Findings suggest that caregiver reactions and appraisals to EL vary, and experiencing EL may affect care decisions that caregivers make on behalf of those with late-stage Alzheimer's disease and related dementia (ADRD). Caregivers seek out information, but few evidence-based resources exist to guide caregivers through these experiences.
3. **Future Directions:** This paper proposes opportunities for research, including qualitative research to understand the context and interpretation of positive and stressful appraisals of EL, assessment of care decisions resulting from experiencing EL, how evidence-based resources affect caregiver decision making, and how educational and training resources affect providers caring for people with ADRD and their caregivers.

Especially difficult transitions for caregivers occur during the grief and readjustment stage, particularly in late-stage ADRD when their relatives' communication is limited and coherent capacity is assumed to be lost.^{8,9} During this stage, caregivers must cope with the inevitability of their relatives' irreversible cognitive and physical function loss while making decisions about care needs and end-of-life plans. It is possible, therefore, that unexpected and spontaneous episodes of lucidity (EL) among people with late-stage ADRD, as have been reported in case studies,¹⁰⁻¹² can also disrupt the caregiver's transition and ability to prepare for change. These lucid episodes, also referred to as paradoxical lucidity, are characterized by spontaneous mental clarity with verbal or non-verbal communication or behavior among people who had previously been thought to lack the cognitive capacity to do so.^{13,14}

There is growing interest in the neuropathology of EL and the clinical implications of whether they indicate disease progression,¹⁴ but how, when, or why these episodes occur is not well understood, and clear scientific definitions of EL are still lacking.¹⁵⁻¹⁷ Even less is known about how caregivers who witness these episodes appraise and react to them, if they consider them beneficial or stressful, or if they prompt changes in how they manage or make decisions about care for their care recipients. To assess caregiver appraisals of EL and what, if any, information they sought out as a result of this experience or to prepare them for EL, we analyzed cross-sectional data from former/current caregivers of people living with ADRD who reported witnessing an EL. This study, one of six funded by National Institute on Aging to advance scientific understanding of lucidity in dementia,¹³ is part of a larger parent study to develop typologies of EL experiences by characterizing their frequency, duration, mode (e.g., verbal, non-verbal),

content of communication, and triggering circumstances. In the parent study, survey data are used to develop preliminary typologies, and then, using qualitative data from in-depth interviews, the typologies are refined.^{18,19} The validity of the refined typologies will then be tested in a subsequent longitudinal study with current caregivers—which will help further characterize EL, establish prevalence estimates, and evaluate how different EL types are associated with caregiver reactions. Given the paucity of data on ELs, findings presented in this ancillary study will inform which questions are used to assess the effect caregiver appraisals of EL have on caregiver strain, quality of life, and bereavement responses in the longitudinal study.

2 | METHODS

2.1 | Sample

Participants were recruited from UsAgainstAlzheimer's, an advocacy group that aims to mobilize participation in research on effective treatments and care quality for ADRD (usagainstalzheimer.org). UsAgainstAlzheimer's administers the A-LIST[®], a unique online community of 10,000 individuals who self-identify either as someone at risk for or with mild cognitive impairment (MCI) or ADRD, a current or former caregiver for someone with ADRD, or someone interested in brain health (alist4research.org). Included in this analysis are current or former caregivers of someone with ADRD who enrolled in the A-LIST and reported witnessing an EL. The UsAgainstAlzheimer's Institutional Review Board approved the study and all participants provided informed consent prior to participating.

2.2 | Procedures

In February 2021, UsAgainstAlzheimer's sent an e-mail to A-LIST participants who had previously identified as current or former caregivers or had never identified their role, but had previously responded to A-LIST correspondence ($n = 3569$). Invitations requested participation from current and former caregivers of someone with ADRD, described EL and the study's purpose, and provided 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 EL: "A lucid experience is an unexpected, spontaneous, meaningful, and relevant communication with your relative, friend or neighbor when they had lost the ability to speak or have personal interactions." Respondents were asked if they had ever witnessed an EL in a relative, friend, or neighbor who has ADRD and were given the option to report up to two episodes.

Of 538 respondents who responded (out of 3569), 58 were not current or former caregivers. Of 480 eligible respondents, 294 (61.1%) responded yes to having witnessed EL and reported 479 episodes. For this analysis, we used 233 respondents with complete demographic information to describe the study sample (episode $N = 441$).

2.3 | Measures

Data included demographic information about the caregiver, care recipient, their relationship, and descriptive information about the witnessed EL(s). Questions on EL were informed by Batthyány and Greyson.¹⁰

Respondents were asked about: (1) their appraisal of the EL (i.e., how positive and stressful it was; rated from 1 = not at all to 5 = very), (2) decisions made as a result of an EL (i.e., close-ended questions with choices including: decisions about medical care, finances, end-of-life planning, living arrangements, personal needs, social needs, and how to provide better care; yes/no), and (3) if, and from whom, they sought out information or education about ELs (i.e., from health-care provider, internet, family member or friend, public educators/media, support, and Alzheimer's Association; yes/no).

3 | RESULTS

Table 1 displays caregiver characteristics and characteristics of the care recipients that had an EL. Nearly all the caregivers were children (67%) or spouses (27%) of the care recipient.

Table 2 summarizes survey results, which are considered exploratory findings. Caregivers, on average, reported 72% of ELs to be (quite a bit or very) positive ($M = 4.00$, standard deviation [SD] = 1.25; range = 1–5). However, they found 17% of ELs (quite a bit or very) stressful ($M = 1.96$, $SD = 1.33$). The positive and stressful appraisals were moderately correlated ($r = -.26$). Ten percent of ELs were appraised to be both stressful and positive. Multivariate models for positive and stressful appraisals revealed that caregivers who are adult offspring ($B = -.46$; $P = .048$) were likely to report lower levels of stress associated with EL (see Table S1 in supporting information). Positive appraisals did not show significant associations with any caregiver demographics.

Overall, 12% of caregivers made changes based on ELs—most commonly modifications to a care recipient's living arrangements, social needs, and medical care, and less frequently on personal needs, strategies to improve care, finances, and end of life planning. Thirteen percent sought out information or educational materials about ELs, mainly from a health-care provider or the internet. More than 50% desired information on why ELs occur, >40% on how to recreate them, and >37% on how best to respond to ELs.

4 | DISCUSSION

In our study, we found that the majority of caregivers who witnessed ELs consider them to be positive. Among caregivers of people with ADRD, positive appraisals of caregiving may help buffer stress,^{20,21} and therefore, it is possible that a positively appraised EL helps safeguard caregivers from stress. Conversely, it is also possible that caregivers who appraise EL as stressful may experience greater stress during

TABLE 1 Self-reported characteristics of caregiver participants and their proxy report of characteristics of care recipients who had an episode of lucidity^a

Variable	Caregiver	Care recipient
Relation to care recipient		
Spouse/partner	27%	—
Child	67%	—
Other relative	4%	—
Friend/neighbor	2%	—
Still living	—	35%
Dementia type ^b		
Alzheimer's disease	—	71%
Vascular	—	11%
Frontotemporal	—	8%
Lewy body	—	6%
Parkinson's	—	2%
Never diagnosed	—	6%
Lived in the same household	—	41%
Age		
Under 50	6%	—
51–60	20%	—
61–70	41%	—
Over 70	32%	—
Female	69%	64%
Non-Hispanic White	85%	—
Education		
Less than high school	0%	8%
High school	12%	39%
More than high school	88%	52%
Marital status		
Married	60%	—
Cohabiting	5%	—
Divorced/separated	9%	—
Widowed	12%	—
Never married	12%	—
Employed (full or part-time)	29%	—

^aCaregiver $N = 233$.

^bMultiple responses.

caregiver role transitions. Most striking, however, is that respondents reported 10% of ELs as being quite a bit or very positive and quite a bit or very stressful, suggesting that some ELs provoke a complex response that may affect role transitions differently. Qualitative data could help elucidate this duality and provide a deeper understanding of the caregiver experience.

TABLE 2 Caregivers' appraisals of lucid episodes, decision-making changes, and seeking-out information

Variable	M (SD)
Appraisals of lucid experiences^a	
(1) Positive experience	4.00 (1.25)
(2) Stressful experience	1.96 (1.33)
Changed decision after lucid experiences?^b	
(1) Decisions about medical care	5%
(2) Decisions about finances	1%
(3) Decisions about end-of-life planning	1%
(4) Decisions about living arrangements	6%
(5) Decisions about personal needs	4%
(6) Decisions about social needs	6%
(7) Decisions about how to provide better care	4%
Seek out information or education materials?^b	
(1) Health-care provider	8%
(2) Internet	8%
(3) Family member/friend	2%
(4) Public educators/media	1%
(5) Support group	.4%
(6) Alzheimer's Association	1%
Found information or educational materials helpful?^b	
12%	
What would you like to know about lucid experiences?^b	
(1) Why they occur	52%
(2) When they occur	26%
(3) How to best respond to a lucid experience	37%
(4) How to recreate the experience	43%
(5) The impact on people with dementia	.4%
(6) How to make them last longer	.4%

^a1 = not at all to 5 = very (asked per episode; episode $N = 441$).

^bCaregiver $N = 233$.

A small but potentially meaningful percentage of caregivers in this study sought out EL information from health-care providers or the internet, suggesting a need for reliable information. As additional data from the parent study emerges on types of EL and its consequences, we will be able to develop reliable educational resources for broad dissemination in partnership with advocacy organizations.

Last, some caregivers in this study made changes to how they manage care after witnessing an EL. Our larger parent study includes a longitudinal study to assess the frequency and outcomes of these planning decisions, including their beneficial or detrimental effects on caregiver and care recipient outcomes, which, in turn, can be used to develop future caregiver interventions, psychoeducation, and epidemiological research on EL. As additional research emerges on EL, health-care providers will also need to be prepared to address questions about EL. They will need to consider caregiver experiences with EL when devel-

oping care plans and provide guidance on caregiver decision making after experiencing EL.²² Developing evidence-based educational materials for providers about EL can help them prepare for conversations with caregivers about what to expect when caring for someone with late-stage ADRD.

Our study has a number of limitations. First, these findings are considered exploratory and potentially hypothesis-generating. With no accepted scientific definition of EL yet,^{10,17} it is possible that some caregivers had difficulty distinguishing cognitive fluctuations earlier in the disease course ("good days and bad days") from ELs in later stages of ADRD. Second, self-reports may have led to recall bias about ELs, especially about decision-making changes after experiencing EL. Qualitative data collection is under way to better elucidate self-reported answers. Third, participants recruited from an Alzheimer's disease advocacy group may not be representative of all ADRD caregivers. Finally, our sample was predominately White (85%) and findings may not be generalizable. More diverse representation in future research is critical for understanding variation in caregiver reactions to EL. The forthcoming parent study will address these limitations.

5 | CONCLUSIONS

Findings suggest that caregiver appraisals of EL are generally positive but also considered stressful among some. Witnessing ELs prompts some caregivers to change or postpone care decisions related to their relative with late-stage ADRD. Few evidence-based resources exist to guide caregivers through these experiences. Future research is needed to build knowledge in this understudied aspect of ADRD and to understand its effect on caregivers.

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CONFLICTS OF INTEREST

Dr. Griffin discloses a contract with Exact Sciences Corp. that is paid to her institution. No other authors report conflicts of interest.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of the article at the publisher's website.

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