

# Understanding Paradoxical Lucidity: Family Caregiver Interpretations of Lucid Episodes Among People With Late-Stage Alzheimer's Disease and Related Dementias (ADRDs)

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**Take-Away:** Family caregivers provide unique context and knowledge about Episodes of Lucidity (EL) in people living with ADRD. Their appraisals are critical for advancing the scientific understanding of EL.

## INTRODUCTION

- **Episodes of lucidity** (EL; sometimes called paradoxical lucidity) are described as the spontaneous, transient return of abilities or communication that had been presumably lost among people living with ADRD.<sup>1-3</sup>
- Current models of ADRD do not adequately account for, explain, or provide data on these spontaneous reversals of cognitive ability.<sup>4</sup> Nor do these models consider how **family caregivers** (FCG) interpret ELs and whether ELs influence how FCGs make **care decisions**.<sup>5</sup>

### For this study, our objectives were:

- To investigate how FCGs experience and attribute meaning to ELs
- To explore how FCGs considered or did not consider changes for the care recipient after ELs
- To use data to refine typologies of ELs developed using FCG survey data

## METHODS

- Participants were current and former FCGs who had previously completed an electronic survey that helped characterize ELs. Those who reported witnessing at least one EL in the survey were eligible.
- Participants were purposively chosen based on the type of EL they witnessed. Four preliminary EL types had been determined after a typology analysis of survey responses.
- Other criteria were also included to assure balancing of perspectives. These included: (a) the relationship to the person with ADRD, (b) whether they lived together, (c) whether the person with ADRD was still living or had died, and (d) FCG race/ethnicity.
- Twenty-four participants were interviewed by phone. Interviews were recorded, transcribed, double-coded, and analyzed to meet study objectives.

## RESULTS

### Meaning making:

- FCGs often assigned meta-physical meaning to ELs and worked to make sense of them.
- ELs were indelible; FCGs could describe them in very specific detail.
- FCG reported they were uniquely qualified to understand the nuanced behavior changes, actions, or “thoughts” that they felt indicated lucidity.

### Consequences of ELs:

- FCGs identified family conflict about how to manage the care recipient's care after witnessing a lucid episode.
- FCGs identified adjustments they made or how they recreated EL conditions into daily routines in order to stimulate another episode.

## RESULTS

### Potential ways to differentiate typologies:

- When in the disease course ELs happen
- Degree of change from pre-EL state to EL state
- Presence of “triggers” that precipitated EL (family engagement, familiar rituals, and life-altering/ending events)
- Coherence of communication (verbal and non-verbal)

## CONCLUSIONS

- Caregivers recall specific details that help them make meaning of ELs and can influence subsequent care decisions.
- FCGs provided context on the interdependence between FCG appraisals, factors associated with a person living with ADRD's disease course, and EL characteristics.
- Future work will attempt to disentangle FCG/observer characteristics from EL characteristics.

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