The Pulse of the Community

CONNECTING THE ALZHEIMER'S COMMUNITY AS PARTNERS IN RESEARCH

The UsAgainstAlzheimer's A-LIST® is an online community of more than 10,000 people living with Alzheimer's and other dementias, current and former caregivers, and those interested in brain health. A-LIST surveys gather data and personal insights to better understand and share the collective experience of living with this disease and caring for a loved one. We call it the "science of us."

What Matters Most

The mission of the A-LIST is to use data to make life better for the Alzheimer's and dementia community. UsAgainstAlzheimer's shares anonymous findings with policymakers, researchers, health care providers, public health officials, drug developers, insurers and others who serve this community to ensure they consider these insights when making decisions affecting people living with the disease and their caregivers.

Lucidity in Demetia

Lucidity *(noun)*:
Clearness of thought or style; a presumed capacity to perceive the truth directly and instantaneously (Merriam-Webster)

People who are living with late-stage Alzheimer's disease or dementia often reach a point when communication is limited or not possible. However, sometimes they can have moments when they can suddenly express themselves verbally or non-verbally. These are called "episodes of lucidity" (ELs). Little is known about why these episodes happen. Even less is known about how caregivers feel about witnessing them.

The Study

The A-LIST is part of an important national study funded by the National Institutes of Health and led by Dr. Joan Griffin of Mayo Clinic to better understand lucid episodes. Over five years, we are researching the experiences of caregivers who see them happen. The study aims to learn about the frequency, duration, and content of any communication, as well as circumstances that trigger lucid episodes. This research will also improve understanding more generally of Alzheimer's and related dementias.

Phase 1

During the first two years of the study, we surveyed and spoke with A-LIST caregivers about whether they had witnessed lucid episodes in their loved ones. Caregivers were asked questions about whether they found these episodes positive or not, how long they lasted, and if caregivers made decisions based on the episodes, or tried to find resources.

Survey Results

Note: "Episodes of lucidity" are also referred to as "ELs," "lucid experiences" and "paradoxical lucidity."

- More than 60% of caregivers (n = 294, 62%) reported witnessing ELs with their care recipient over the course of their dementia.
- Most episodes happened in late stages of dementia (71%).
- Only 10% happened within 7 days before death.
- Most episodes (71%) lasted <30 minutes.
- About half the episodes were characterized by uncharacteristic speech and communication.

Most caregivers (72%) who witnessed lucid episodes said it was a positive experience. 17% said it was stressful. More striking however, is that respondents reported 10% of lucid episodes as being quite a bit or very positive and quite a bit or very stressful. This suggests that some lucid episodes provoke a complex response for some caregivers.

- 12% of caregivers changed care plans because of ELs.
- 13% sought out information about ELs.

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Q: What would you like to know about lucid experiences?

- Why they occur 52%
- When they occur 26%
- How best to respond to a lucid experience 37%
- How to recreate the lucid experience 43%
- The impact on people with dementia .4%
- How to make them last longer .4%

> These initial data suggest caregiver reactions to lucid episodes vary. Caregivers may change or postpone care decisions due to the episodes. And too few resources exist to address caregiver questions about lucid episodes.

Interview Results

In interviews, family caregivers often assigned metaphysical meaning to ELs and worked to make sense of them. The episodes were indelible, and caregivers could describe them in very specific detail. Caregivers reported they were uniquely qualified to understand the nuanced behavior changes, actions or "thoughts" that they felt indicated lucidity.

Publications

Study results have been published and presented in several major journals, national conferences and other outlets.

"Lucidity in Dementia: Emerging Concepts and Data," Symposium, GSA 2022, The Geronotological Society of America, November 2022.

BrainStorm Podcast: Meryl Comer interviews the study's Principal Investigator, Dr. Joan Griffin of Mayo Clinic, July 2022.

"Understanding Paradoxical Lucidity: Family Caregiver Interpretations of Lucid Episodes Among People With Late-Stage Alzheimer's Disease and Related Dementias (ADRDs)," Alzheimer's Association International Conference 2022.

"Caregiver appraisals of lucid episodes in people with late-stage Alzheimer's disease or related dementias," Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring, Volume 14, Issue 1, June 23, 2022.

"Early Descriptions of Family Caregivers' Experiences With Unexpected Lucidity," Innovation in Aging, Volume 5, December 17, 2021.

"Advancing the Science on Unexpected Episodes of Clarity and Lucidity in People with Dementia," Symposium, GSA 2021, The Geronotological Society of America, November 2021.

"Episodes of lucidity (paradoxical lucidity): A survey of family caregivers of persons with dementia," International Psychogeratrics, November 1, 2021.

Episodes of lucidity (paradoxical lucidity): A survey of family caregivers of persons with dementia, presentation, 21st International Psychogeratric Association International Congress November 2021.

Phase 2

Starting in early 2023, we will recruit caregivers for a year-long survey series exploring lucid episodes in greater depth. Participants will answer short monthly surveys with 3 longer surveys at key points during the year. We will develop educational materials for caregivers, healthcare providers and the wider dementia community to improve understanding of this powerful phenomenon in Alzheimer's and related dementias.

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