

- how is the lived experience journey in Alzheimer's shaped by the complexities of agitation and other behavioral aspects of the disease;
- how can insights from "social listening" analysis structure our understanding of these journeys;
- how can we understand the dyad journey of the person with Alzheimer's and the care partner as well as the interactions therein, particularly through the lens of agitation.

This project, "Mapping the Lived Experiences" recasts the Alzheimer's journey to better reflect these priorities. We offer a visual interpretation of the journey with the rationale and proof points that underpin it.

"Mapping the Lived Experiences" prioritizes agitation and other behavioral aspects of Alzheimer's as pivotal, enduring challenges on the disease journey. We frame the journey into two overarching phases: "the first loss," which accounts for the more widely recognized symptoms of the disease, such as memory loss and declining cognitive function; and "the second loss," which is characterized by agitation and behavioral aspects of the disease. We structure the journey around "milestone moments" – moments when both the person with Alzheimer's and the care partner recognize that the disease has taken a major progression.

The "milestones" moment framework reflects an interpretive framework developed through an ongoing "social listening" research project. This social listening research allows analysis of the online conversation as it is happening in social channels and discussion boards, and it provides a poignant counterpoint to quantitative market research insofar as it illuminates the unfiltered, unmitigated experiences as articulated by the people who are learning in real-time to manage and live with Alzheimer's. From social listening insights and analysis, our research posits that journeys – for both the person with Alzheimer's and the care partner – are not linear, straight-line trajectories, but jagged, fragmented paths marked by "milestone moments" that shape thinking, understanding, and behavior.

"Mapping the Lived Experiences" offers a dyad visualization and articulations, as it fuses the journeys of the person with lived experience and the care partner together in the same visual space. This approach reveals how, over time, these journey relate, inform, and ultimately depart from one another. This dyad offers new insights into both the lived experience and care partner journeys.

### **533 - "Agitation and End-of-Life: Towards an Advance Directive that Prepare for Agitation and Behavioral Symptoms in Alzheimer's Disease"**

**Presenter(s)** Mary Chi Michael

#### **Organization(s)**

- Chair, The Global Council on Alzheimer's Disease
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#### **Abstract (400 words)**

Advance Directives provide legal documentation of a person's wishes regarding medical treatment and care, allowing people and their families to decide in advance how care and treatment should be provided at end-of-life when a person is no longer capable of making independent decisions. For people living with advanced stages of Alzheimer's, Advance Directives give specific, life-altering instructions to ensure a person's will is being met. Yet Advance Directives that anticipate for the eventualities of Alzheimer's Disease often fail to specifically prepare for the care and treatment decisions prompted by agitation and other behavioral aspects of the disease. This is a major oversight.

“Agitation and End-of-Life: Towards an Advance Directive that Prepare for Agitation and Behavioral Symptoms in Alzheimer’s Disease” proposes a framework for how Advance Directives can prepare for the unique decisions that arise as a person experiences agitation and other behavioral symptoms of Alzheimer’s.

The framework proposed in this project draws from the recent development of Psychiatric Advance Directives led in part by the American Psychiatric Association, which have pioneered the use of Advance Directives for anticipated behavioral challenges. Specifically, Psychiatric Advance Directives allow individuals to specify in advance which treatments may be administered in response to acute episodes of psychiatric illness at a time when someone is unable or unwilling to provide consent. Our project contends that the mechanisms underlying Psychiatric Advance Directives be modeled but modified to help people, families, and providers prepare for agitation and the behavioral aspects of Alzheimer’s.

Specifically, we propose a four-part framework for Advance Directives to prepare for agitation and other behavioral aspects of Alzheimer’s:

1. **Psychiatric medications.** What treatments may – or may not – be used to manage agitation or other behavioral disturbances?
2. **Agitation prevention and de-escalation.** What strategies and techniques can caregivers employ to mollify agitated behaviors? How should caregivers respond to episodes of agitation?
3. **Lifestyle preferences and values.** What values – religious or otherwise – should guide care and treatment?
4. **Information sharing and access.** When and how should caregivers, medical professionals, and family members be notified – or share information about – behavioral disturbances?

It is well established in the scientific and medical literature that agitation and behavioral aspects of Alzheimer’s can cause severe difficulty for families as the disease progresses. Advance Directives that prepare for agitation can help to create a plan and ease the challenges prompted by agitation and other behavioral aspects of Alzheimer’s.

## 534 - Grief in de elderly and its impact

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**Introduction** With coronavirus disease 2019 (COVID-19) a lot of people have succumbed and older adults were disproportionately affected. (1,2) Also, grief is encountered frequently in clinical practice with the elderly, and can be defined as the natural response to the death of a loved one. Still, when a failure of adaptation occurs then a Prolonged Grief Disorder (PGD) can be diagnosed, which has been recently included in ICD-11. The principal feature of PGD is a persistent preoccupation or an intense longing for the deceased that lasts longer than 6 months after the death. (3)

**Objective:** Comprehend the grief in the elderly and its implications in their health.

**Method:** The author conducted a literature review by searching the Pubmed database using the keywords elderly; grief; complicated grief; covid-19

**Results:** PGD is relatively prevalent among the elderly and has been associated with some variables related to the death time of the deceased, being the prevalence inversely correlated with the deceased’s. (4, 5) Additionally, older adults present a higher risk of developing PGD when they are less