Navigating Systemic Gaps in Emergency Preparedness: The Experience of Individuals with Dementia and Their Caregivers During Crisis Events

Ashley Johnson

Alzheimer's disease (AD), the most common form of dementia, is a brain disorder marked by the gradual decline of cognitive abilities such as memory, reasoning, and decision-making, ultimately disrupting independent daily functioning. As symptoms advance, individuals with AD become increasingly reliant on caregivers and structured support systems for safety and routine care. During emergencies – such as natural disasters or evacuations – these individuals face heightened risks, including disorientation and anxiety, which can exacerbate symptoms and overwhelm both patients and caregivers, especially when regular services are disrupted.

Despite a growing population of individuals with dementia, emergency preparedness systems often fail to account for their specific needs. Many protocols overlook dependence on third-party caregiving, limited transportation, and communication barriers, putting this population at increased risk.

My Capstone project explores the experiences of individuals with dementia and their caregivers during emergencies, focusing on the 2025 Los Angeles wildfires. I conducted semi-structured interviews at my internship site, WISE and Healthy Aging – a dementia-focused adult day care center – to collect qualitative data on preparedness, service gaps, and future planning. Through an ethnographic approach grounded in a disability studies framework, my research aimed to identify social and structural barriers and inform the development of more inclusive disaster readiness protocols.

Although Alzheimer's disease and related dementias are rarely situated within the realm of Disability Studies, they embody many of the core issues the field seeks to address: social exclusion, dependency on care networks, and systemic inaccessibility. This project contributes to a growing call to reframe dementia not solely as a medical or aging issue, but as a disability justice issue – one that demands recognition and rights-based responses. By centering the lived experiences of people with dementia, my research aims to broaden the scope of Disability Studies and advocate for more inclusive policy and care infrastructure.

Disability Studies, and the courses I have taken at UCLA, have completely reshaped how I understand and engage with the concept of "difference." Rather than viewing disability as an individual impairment, I have come to adopt the social model perspective that emphasizes the ways in which our environments, systems, and institutions create barriers. This shift has influenced how I now think about education, employment, public spaces, and everyday experiences like traveling – not as inherently inaccessible, but as sites of potential reform and transformation. These courses have helped me deconstruct the notion of "normalcy," and instead focus on how *we* can intentionally build a world that is inclusive by design, where all people are valued and accommodated, not just those who are able-bodied. This mindset has become second-nature; I now actively assess the world through a critical lens and envision how it can be more inclusive.

My capstone project reflects this lens by exploring the experiences of individuals with dementia – a topic deeply tied to both my personal and professional aspirations. As someone hoping to pursue a career in neuroscience, my research interests in Alzheimer's disease and other neurodegenerative conditions are fueled by my mother's diagnosis and her rapid progression. Yet, it wasn't until engaging with Disability Studies that I began to challenge the medicalization of cognitive decline and view dementia as a disability. My project aims to promote a rights-based framework that affirms the dignity, identity, and needs of individuals living with dementia. I believe that by naming dementia as a disability, we open the door to more compassionate policies, better emergency preparedness, and social acceptance that values these individuals not for who they once were, but for who they are now. Ultimately, my work seeks to bridge the gap between neuroscience and disability justice, and to contribute to a more equitable and inclusive society for all.