Understanding the evolution of patient burden across the severity stages of Alzheimer's Disease using online social media

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Background

- Patients and caregivers living with Alzheimer's Disease (AD) are actively using online social media to garner support, ask or answer questions and/or discover new disease management strategies from others in similar situations.
- Across the different clinical severity stages of AD, patients and caregivers participate in social media conversations to varying degrees. Reporting by both groups serve as an opportunity to compare and contrast issues independently shared by patients and caregivers.
- Analyzing unsolicited self-reporting across social media represents a novel approach to learn about patient burden compared with traditional research methods such as surveying and/or focus groups, and can lead to novel insight generation.

Objectives

- The role of the caregiver becomes increasingly pronounced as AD progresses in patients from Mild Cognitive Impairment due to AD (MCI-AD), through to Early-AD (E-AD) and then to Moderate-Severe AD (MS-AD) stages.[1]
- The aim of this study is to understand how spontaneous online conversations by patients and caregivers can uncover differences in priority issues shared by both sets of reporters, across the different stages of AD, as the disease progresses.
- By understanding these differences, the goal is to inform how to tailor patient-centric diagnostic, disease and lifestyle management approaches over the course of disease and also how to incorporate these findings into clinical research programs.

Methodology

- Online narratives were analyzed across 84 publicly available social media sources from January 1998 and December 2019 (Fig. 1). Password-protected sites were not accessed and personally identifiable information was not collected.
- Narratives were qualified into the sample if symptoms and impairments were reported by patients or caregivers actively disclosing an AD diagnosis or treatment regimen (Fig. 2).
- The RLytics Natural Language Processing (NLP) platform was used in combination with manual curation to analyze Social, Physical, Emotional, Cognitive, and Role Activity (SPEC-R) issues extracted from patient and caregiver narratives to evaluate patient burden in MCI-AD, E-AD and MS-AD (Fig. 3).
- Standardized medical taxonomies including the WHO International Classification of Functioning, Disability and Health (WHO-ICF) and the Unified Medical Language System (UMLS) were used to support domain classifications and to perform frequency analysis across reporting subgroups.

Figure 1. Reports by social media source

Social Media Source	Total Narratives	Total (%)
Disease Focused Forums *e.g. Alzheimer's Forum*	83,898	74.6%
General Social Media *e.g. Twitter, Reddit*	10,909	9.7%
General Health Forums *e.g. Healthboards*	10,009	8.9%
General Health Social Networks *e.g. Dailystrength*	6,185	5.5%
Treatment Review Websites *e.g. AskaPatient*	1,463	1.3%
Total	**112,464**	

Figure 2. Report and reporter qualification funnel

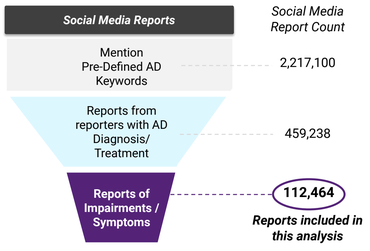
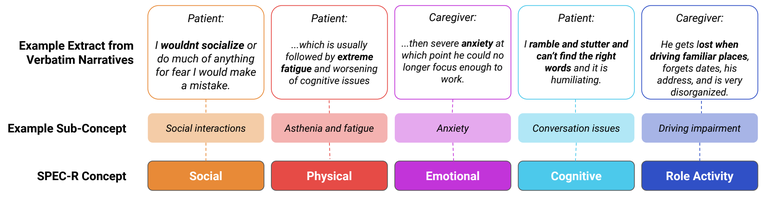


Figure 2. Overview of concepts and sub-concepts included in the SPEC-R categorization framework



Results

- 112,464 narratives from 692 patients and 10,174 caregivers were qualified into the final analytic sample with 333 patients clinically diagnosed for MCI-AD and 359 for E-AD. No individuals with MS-AD were captured over the social media forums. Of the caregivers, 971 were caring for patients with MCI-AD, 3,776 for patients with E-AD, and 5,427 for patients with MS-AD. See Fig. 4.
- Among patients with MCI-AD and their caregivers, 95.5% of patients and 83.0% of caregivers discussed cognitive issues, e.g. memory impairments. 61.0% of patients and 51.4% of caregivers shared emotional issues, e.g. anxiety and depression.
- Among patients with E-AD and their caregivers, emotional issues were the most frequently discussed by both patients (93.6%) and caregivers (53.5%), e.g. anxiety, depression and other emotional experiences. Cognitive issues followed, and were shared by 86.9% of patients and 39.6% of caregivers.
- Among caregivers for patients with MS-AD, 42.7% reported on emotional issues and 20.7% on physical issues, e.g. fatigue and agitation.

Figure 4. Reporter types by disease stage (n=10,866)

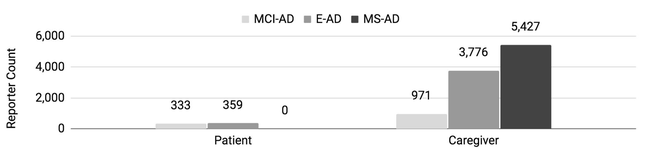
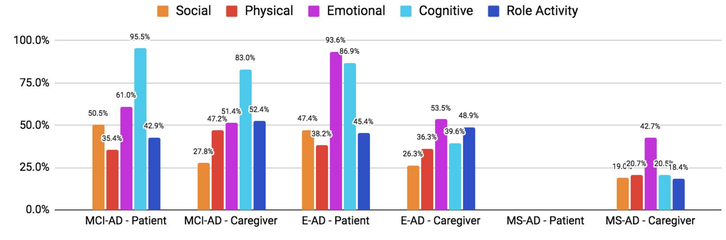


Figure 5. Symptom and impairment reports classified by reporter types and disease stage (n=10,866)



Conclusion

- Individuals with MCI-AD or E-AD were active on social media to share their experiences and challenges while those with MS-AD appeared to no longer participate in online communications relating to their illness. Caregivers were active on social media across disease severity stages.
- The frequencies of caregiver reporting on prominent patient challenges differed from that of patient self-reporting. Notably, in comparison to caregivers, patients disproportionately report emotional, cognitive and social symptoms and impairments, whereas physical and role activity issues are more frequently reported by caregivers.
- The differences in patient and caregiver self-reporting may indicate a caregiver bias towards reporting on issues that directly affect caregivers as opposed to the patients themselves. For example, in the early stages of the disease caregivers may feel greater burden from a patient's *inability to drive a car* versus *anxiety issues*. Further evaluation of these concepts should be conducted to validate the differences across the two reporter types, potentially using proactive research approaches (e.g. surveying) and/or capturing feedback from healthcare professionals.

References

[1]Brodaty H, Donkin M. Family caregivers of people with dementia. Dialogues Clin Neurosci. 2009;11(2):217-228.