

Dementia care research (research projects; nonpharmacological) / Assessment and care planning

Evaluation of patient burden using online social media in mild cognitive impairment

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Email: amir_tahami@eisai.com**Abstract**

Background: Detection and diagnosis of Mild Cognitive Impairment due to Alzheimer's Disease (MCI-AD) can be challenging due to the subtlety of changes in early stages of disease progression. As a result, opportunities to capture the patient burden in MCI-AD can be limited.

Method: We used Natural Language Processing (NLP) to analyze challenges and issues that were the most frequently reported online by patients living with MCI-AD and caregivers. Patients' self-reports and caregivers' reports on patients were identified based on online narratives posted between January 1998 and December 2019 across 84 social media sources. The RLYtics NLP platform was used in combination with manual curation to codify verbatim symptoms and impairments against standardized medical taxonomies such as WHO-ICF and MedDRA, and further into the following categorizations: **S**ocial, **P**hysical, **E**motional, **C**ognitive, and **R**ole Activity (**SPEC-R**).

Result: 63,933 narratives from 311 patients with MCI-AD and 1,454 caregivers were qualified into the sample for analysis. The most frequently reported issues varied between patients and caregivers. Cognitive issues (e.g. memory impairments and comprehension-related) were the most frequently reported by both groups, however, patients reported at a higher rate. This may suggest a deeper concern with losing cognitive ability felt by patients themselves at the disease stage of MCI. This is further supported by a higher reporting rate of anxiety and depressive disorders among patients relative to caregivers. In contrast, certain role activity, physical and social issues (e.g. driving, fatigue, walking and mobility, relationships with spouse or partner) are reported by caregivers at a higher rate than patients, suggesting that these issues may have a greater impact on the daily lives of caregivers or may be more readily recognizable than cognitive issues.

Conclusion: The SPEC-R framework helps identify, understand, and prioritize the most pressing concerns at the symptom and functional level by patients and caregivers. It can uncover areas of disease burden in MCI-AD that are less frequently associated with MCI, particularly in the non-cognitive domains, that may not be sufficiently captured by early diagnostic processes in the clinical setting.

TABLE 1**Table 1. Most frequently reported symptoms and impairments across SPEC-R categories**

SPEC-R Category	Symptoms and Impairments	Patients		Caregivers		Total	
		n = 311	%	n = 1,454	%	N = 1,765	%
Cognitive	Memory impairments	297	95.5%	1,168	80.3%	1,465	83.0%
	Comprehension issues	210	67.5%	876	60.2%	1,086	61.5%
	Conversation issues	223	71.7%	853	58.7%	1,076	61.0%
Emotional	Anxiety disorders	190	61.1%	747	51.4%	937	53.1%
	Depressive disorders	171	55.0%	619	42.6%	790	44.8%
	Anger and aggression	111	35.7%	600	41.3%	711	40.3%
Role Activity	Driving impairments	127	40.8%	733	50.4%	860	48.7%
	Employment	122	39.2%	566	38.9%	688	39.0%
	Financial issues	129	41.5%	537	36.9%	666	37.7%
Physical	Asthenia & Fatigue	97	31.2%	662	45.5%	759	43.0%
	Walking and mobility issues	100	32.2%	595	40.9%	695	39.4%
	Insomnia	33	10.6%	32	2.2%	65	3.7%
Social	Social interactions	160	51.4%	420	28.9%	580	32.9%
	Relationships (Spouse)	17	5.5%	348	23.9%	365	20.7%
	Relationships (Friends/Family)	44	14.1%	165	11.3%	209	11.8%