



RLS Reveal

Incorporating Novel Real-World Data Across
the Drug Development Continuum:
Leveraging the Value of Digital Social Media

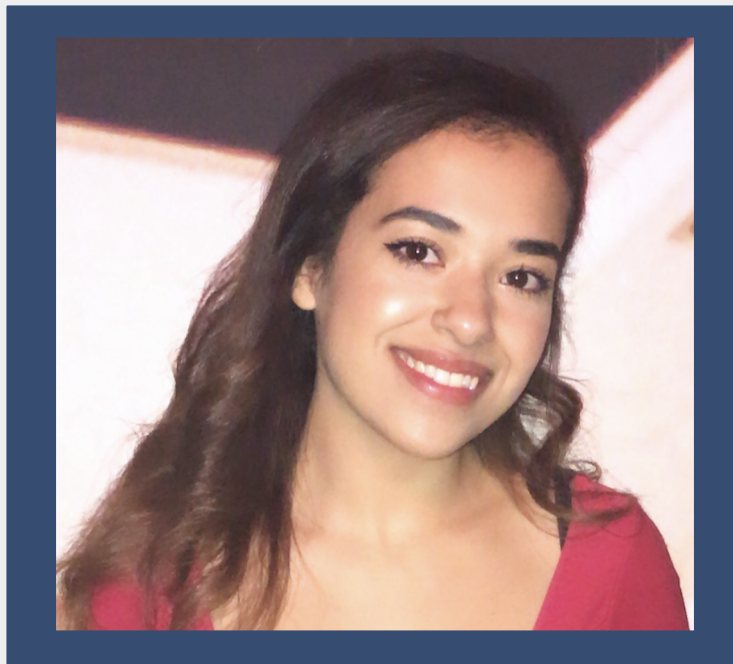
Dr. Nardin Farid

Solution Strategy & PharmD

October 2021



Dr. Nardin Farid



Strategy Lead, Real World Patient Analytics

AGENDA

- Novel Insights From Social Media Epidemiology
- Defining “Social Media Epidemiology”
- How it works
- Q&A / Contact





Real Life Sciences

**Revolutionizing outcomes research
through advanced insight generation and
cutting-edge Natural Language Processing
while protecting patient privacy**

 RLS Protect

Data anonymization, redaction and risk assessment for Health Canada and EMA policies for new drug applications.

- **Quantitative risk assessments**
- **Voluntary and Regulatory submissions (EMA, HC)**
- **Anonymization of clinical and RWD e.g. social**
- **Fit-for-purpose SaaS solution and expert Managed Services**

 RLS Reveal

Takes unstructured Social Media RWD and structures it using advanced NLP for a better more complete understanding of a disease state.

- **Social Media Real World data**
- **Data structuring and categorizations**
- **Noise elimination**
- **Unmet needs, market access and HEOR insights**
- **Novel data leads to informed decision making**





Novel Insights From Social Media Epidemiology

**Patient Journey**

Some teams struggle to hear the patient's voice

**Noisy Inaccurate Data**

Some data is noisy, inaccurate and therefore not useful

**Unstructured Data**

Many Sponsors lack a scalable and repeatable methodology for organizing social data

**Small Sample Population**

The data that is available may represent a small subset population and may lack direct patient perspectives

Industry Observations

INFLUENCE

Surveys show that more than 40% of people are influenced by social networks in their health choices

FUTURE USE

Of those between 18 and 24 years of age, 90% say they trust medical information shared on social networks

QUALITY OF CARE

According to 60% of doctors, the effective use of social media improves the quality of care provided to patients

ADVANCED TECHNOLOGY

Leading technology advancements can better support processing and analysis of unstructured data



Dose Splitting

The Sponsor sought an evaluation of hypoglycemic events among patients in the real world. Social Media Epidemiology identified a pattern of dose splitting to prevent hypoglycemia.

Compliance

The data also identified patterns in patient discontinuation of medication due to hypoglycemic events on the prescribed directions.

Lost Revenue

Gaining these insights allowed the Sponsor to identify millions in lost revenue and make changes to address these issues.

G-CSF–Induced Bone Pain

Bone pain is a common side effect after both filgrastim and pegfilgrastim injection. RLS was engaged to evaluate social media real world data to find a possible solution.

Antihistamine

Patients perspectives on social media indicated that after taking an antihistamine, pain was reduced.

Standard of Care

The Sponsor leveraged the Social Media Epidemiology learnings to direct future trials resulting in improved treatments for patients.





Gaps in Care

Using Social Media Epidemiology, gaps in care such as Social, Physical, Emotional, and Functional challenges were identified when comparing clinical outcome assessments to patient reported impairments.

- Anxiety
- Stress
- Aggression

Diagnostic/Screening Tools

Insights from Social Media Epidemiology directed focus to development of improved tools that address the specific patient reported needs leading to optimized QoL.

Cognitive deficiencies were well captured, however, patient burden with **Social, Physical, Emotional, and Functional** challenges was only partially represented in the selected instruments.

Social Media Source	Total Narratives	Total (%)
Disease Focused Forums <i>e.g. Alzheimer's Forum</i>	83,898	74.6%
General Social Media <i>e.g. Twitter, Reddit</i>	10,909	9.7%
General Health Forums <i>e.g. Healthboards</i>	10,009	8.9%
General Health Social Networks <i>e.g. Dailystrength</i>	6,186	5.5%
Treatment Review Websites <i>e.g. AskaPatient</i>	1,463	1.3%
TOTAL	112,464	

Alzheimer's Disease: Quantifying Patient and Caregiver Insights from Self-Reported and Specialized Social Media Data

Abstract

Analyzing patient and caregiver reported opinions, perspectives, and decision-making from specialized social media sources was used to augment the understanding of unmet patient and caregiver needs that may not be captured using traditional methods such as prospective surveys. Natural Language Processing (NLP) was used to aggregate and analyze the most frequently reported issues reported online by patients and caregivers living with neurodegenerative diseases. Using Real-Life Science's proprietary SPEC-R categorization framework, the data yielded that individuals register a whole spectrum of observations, perspectives, and complaints that are not readily captured by traditional disease instruments and may not be visible or well understood by clinicians, HCPs, and/or researchers.

Introduction

For neurodegenerative diseases, the best opportunity for patients and caregivers to benefit from available treatments, enroll in clinical trials, and/or express their wishes is in the early stages of the disease – hence the importance of early detection. Social media represents an opportunity to passively observe and analyze patients in the earliest stages of the disease, in addition to potential pre-disease patient candidates, even before they are "captured" by the traditional healthcare system mechanisms. This study aimed to capture a better understanding of the disease burden across all

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stages of diseases by capturing online patient and caregiver self-reported narratives using social media and mapping them to clinical assessment instruments commonly used in neurodegenerative research and patient screening.

We aimed to evaluate what burdensome functional impairments and symptoms can be extracted from real-world, unguided narratives, with an initial focus on specialized social media, and established the applicability of using software-driven Natural Language Processing and data mining approaches to enhance research into self-reported issues.

Data Collection and Specialized Social Media Sources

We collected patient and caregiver narratives from a wide range of generalist and specialist social media sources – Disease-focused forums contain the most engaged reporters made up of patients and caregivers.

Social Media Source	Total Narratives	Total (%)
Disease Focused Forums <i>e.g. Alzheimer's Forum</i>	83,898	74.6%
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Treatment Review Websites <i>e.g. AskaPatient</i>	1,463	1.3%
Total	112,464	

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rate.

Patients' higher incidence of reporting may suggest a deeper concern with losing cognitive ability felt by patients themselves at an earlier disease stage. This is further supported by a higher reporting rate of anxiety and depressive disorders among patients relative to caregivers.

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patient-centric diagnostic, disease, and lifestyle management approaches throughout the disease.

Our sample size totaled 10,886 self-reported narratives. Caregiver narratives totaled 10,174 while 692 patient narratives were collected and analyzed. Patients' cognitive issues were classified as mild, early, or moderate-severe.

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

Amir Abbas Tahami Monfared, MD, PhD¹, Yaakov Stern, PhD², Michael C. Itzary, MD, MPH³, Stephen Doogan⁴, Nathan Artzi⁵, Qianwu Zhang, PhD⁶

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College of Physicians and Surgeons, Columbia University, New York USA, ³Real Life Sciences, Inc., New York USA

Background

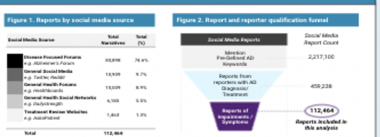
- Patients and caregivers living with Alzheimer's Disease (AD) are actively using online social media to gather support, ask or answer questions and/or discover new disease management strategies from others in similar situations.
- Across the different clinical severity stages of AD, patients and caregivers 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 unselected 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.
- 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 traditional research programs.

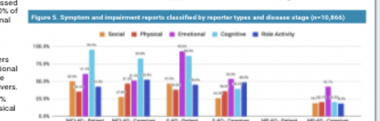
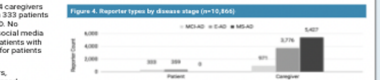
Methodology

- 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-RI) 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.



Results

- 112,464 narratives from 692 patients and 10,174 caregivers were qualified into the final analysis sample with 373 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 4,427 for patients with MS-AD. See Fig. 4.
- Among patients with MCI-AD and their caregivers, 95.3% 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 (53.6%) and caregivers (53.5%), e.g. anxiety, depression and other emotional experiences. Cognitive issues followed, and were shared by 46.9% of patients and 39.4% 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.



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 disease. Caregivers were active on social media across disease severity stages.
- The frequencies of caregiver reporting on premature 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

¹Brodney H, Doonan M. Family caregivers of people with dementia. *Dialogues Clin Neurosci*. 2009;11(2):217-228.

Understanding the Impact of COVID-19 Pandemic on Patients with Alzheimer's Disease and Caregivers Using Online Narratives On Social Media

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Background

- Patients and caregivers living with Alzheimer's Disease (AD) are actively using online social media to gather support, ask or answer questions and engage with others in similar situations.
- The COVID-19 pandemic has disproportionately impacted individuals with pre-existing health conditions, notably amongst those requiring long-term care.
- For the safety of the patients and staff, many research activities such as interviewing or observing patients in-person ceased (1). Social media listening offered a unique opportunity to observe patient and caregiver narratives during the pandemic.

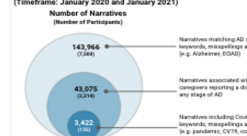
Objectives

- This study aims to describe the challenges of people with Alzheimer's disease (AD) and their caregivers experienced during the pandemic.
- Additionally, the study intends to gather narrative reports of disease progression after a COVID-19 diagnosis. These narrative reports are from caregivers and also patients.
- Lastly, the pandemic and associated shut-down orders have added to the burden of illness. To the best of our knowledge, these changes have not yet been studied. We investigate the reported changes in the burden of illness.

Methodology

- We used the Rlytics NLP (Natural Language Processing) platform to analyze key changes and issues that were shared online over 47 social media sites by patients living with AD and caregivers during the COVID-19 pandemic between January 2020 and January 2021. A total of 3,422 narratives from 135 social media participants were included in the sample (121 caregivers and 14 patients).
- No narratives were collected from password-protected sites and personally identifiable information not collected. Age identifiers such as age were aggregated before inclusion in the dataset.
- The narratives were collected from pre-existing, unlogged, patient and caregiver discussions. The geographical locations of the users included more than 10 countries. For each narrative, we collected data on the date, time, username, and text including discussion, thread title, and blog post title. Narratives were included in the sample based on a multi-stage filtering process based on a series of keywords (see Fig. 1).

Figure 1: Inclusion and Exclusion of Online Narratives for Analysis (Timeframe: January 2020 and January 2021)



Results

- The 3,422 narratives were analyzed and reported in aggregate categories, including extensive descriptions on the worsening of AD, difficulties in understanding and maintaining roles of making and social distancing, limited opportunities of social interactions, reduced caregiver availability and emotional disturbance or exacerbation with fear, anxiety, and loneliness.
- Disease worsening manifested with or without COVID-19 diagnosis, leading to increased reliance and need for caregiver assistance and declining patient wellbeing. The patient challenges were compounded by increased caregiver burden, expressed through the social media on disruptions to Work from Home routines and the need for additional caregiver support to sustain household income.
- The caregiver narratives revealed a range of challenges, including common issues of getting access to COVID-19 vaccines and unique issues of having to remind or assisting patients with handwashing, social distancing, or staying at home. Patient disease progression resulting from restrictive caregiver access to long-term care facilities was frequently communicated online by the caregivers, highlighting increased caregiver emotional stress that led to anger, frustration, crying, loneliness, depression and emotional fatigue.
- Patient narratives allowed a variety of concerns including availability of vaccines, emotional impacts of COVID, demands on caregivers, and isolation from loved ones.

Source	Patients	Caregivers
Alzheimer's Association Facebook Group (New York, NY)	10 narratives from 10 patients with AD. The majority of reports were about the challenges of understanding and maintaining roles of making and social distancing, limited opportunities of social interactions, reduced caregiver availability and emotional disturbance or exacerbation with fear, anxiety, and loneliness.	10 narratives from 10 caregivers. The majority of reports were about the challenges of getting access to COVID-19 vaccines and unique issues of having to remind or assisting patients with handwashing, social distancing, or staying at home.
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Conclusion

- This social media study using NLP uncovers a broad range of challenges experienced by patients with AD and the caregivers during the COVID-19 pandemic. Given that in-person social interactions were limited during the pandemic, social media offered a valuable platform to capture real-world feedback from a remote standpoint.
- Both patients and caregivers appear to have suffered unique health, cognitive, social, emotional, interpersonal, and daily living burden, resulting in worsening of disease and declining wellbeing. The untoward consequences may well likely surpass the pandemic, leading to prolonged deleterious impact in patient and caregiver personal health crisis with AD.
- Subsequent analysis into the patient and caregiver experience following widespread vaccine rollouts would be useful to inform whether or not the issues identified in this study persist.

References

¹ Alzheimer's Disease Research Enterprise in the Era of COVID-19/SARS-CoV-2. *Alzheimer's Demet*. 2020;14(4):587-588. doi:10.1002/alz.12093
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7161993/>

Genetic Testing in Alzheimer's Disease: Concerns and Consequences

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Objectives

- To gain insights about the genetic testing in AD from social media narratives posted by patient, caregiver, healthcare provider.

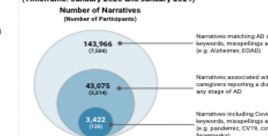
Background

- Increasingly, patients are opting for genetic testing for APOE-ε4 in Alzheimer's disease in the presymptomatic stage (1). However, patients may have concerns around genetic testing and also may need more information after the results are obtained. Social media has become a preferred mode of gathering information about genetics, genomics, and genetic disorders including rare diseases (2). A systematic study of social media narratives from patients with AD and their caregivers can provide further insights into the genetic testing in AD.

Methodology

- In this project, we used the Rlytics Natural Language Processing (NLP) platform and manual curation to aggregate and analyze social media narratives. These online narratives included in our search frequently reported issues experienced by patients, caregivers, and healthcare providers.
- The posts were extracted from AD-specific social media using the following search terms: "APOE" or "Genetic Testing". Additionally, we extracted posts from non-AD-specific social media properties using only the "APOE" search terms - "genetic testing" would have returned too many non-APOE related posts. Rlytics uses syntactic/relational concept models to classify the ways in which medical conditions and functions are reported in raw text. These terms and their relationships with each other, in particular diagnosis relation, function impairment relation, were analyzed using the NLP platform.

Figure 1: Inclusion and Exclusion of Online Narratives for Analysis (Timeframe: January 2020 and January 2021)



Results

The total number of posts included in this analysis was 2,723. These posts were made by 1,549 total unique reporters. A total of 21 themes were extracted from the narratives. From further analyses of these themes, five main categories emerged and overall conversations around APOE testing can be summarized in these five categories:

- 1) Patients and caregivers seeking support and education - narrators needed more information to understand the test applicability/feasibility/validity. The validity of the test for early-onset AD was questioned. Also, they wanted to understand the testing rationale. Narrators wondered if testing could help explain unexplained neuro-symptomatology, testing characteristics/approaches. Narrators were confused with HCP recommendations against testing or genetic counseling. They sought additional patient support post-test results.
- 2) Access concerns - narrators expressed concern around access to testing issues such as cost of testing, location or lab, and physician or personal. High costs (~\$8000) were a barrier to conduct the test. Narrators also had employment concerns such as workplace harassment or job loss after test results.
- 3) Emotional impact of results on self and family - narrators expressed emotional concerns such as they need to prepare for a positive diagnosis. They also indicated emotional relief upon receiving negative test results. Narrators with familial Alzheimer's disease were concerned about child inheritance.
- 4) Concern around privacy of the results impact on insurance coverage or employment - narrators were worried about their health information being sold to insurance companies, resulting in unfavorable insurance coverage or any other financial product for test pre-existing condition diseases.
- 5) General uncertainty on what the next steps would be after receiving results - narrators were worried about the urgency for testing and then managing positive results. They were nervous about support groups specific for test-negative impairment. Narrators were not sure about proactive AD drug prescribing after positive test results, or participating in clinical trials for genetic testing. These concerns were also expressed by healthcare providers for patient-centered care and support systems.
- 6) Go into more detail about patients or caregivers on help people



Conclusion

Genetic testing for APOE-ε4 for probable AD is a widely discussed topic on social media. Social media narratives posted by patients, caregivers, and healthcare providers include a wide range of positive and negative issues around genetic testing in AD. These issues include concerns about the testing itself and concerns around the consequences of testing. Using NLP these social media narratives can provide us actionable insights that are useful in delivering patient-centered care.

References

¹ Alamy M, Alamy KA, Alamy AD, et al. Public Willingness to Undergo Presymptomatic Genetic Testing for Alzheimer's Disease. *Neurosci Res*. 2019;2019:2570513. Published 2019 Mar 3. doi:10.1155/2019/2570513
² Allen CD, Anderson R, Khoury MJ, Roberts MC. Current Social Media Conversations about Genetics and Genomics in Health: A Twitter-Based Analysis. *Public Health Genomics*. 2018;21(1):23-30. doi:10.1155/2018/4381

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

Amir Abbas Tahami Monfared, MD, PhD¹, Yaakov Stern, PhD², Michael C. Irizarry, MD, MPH¹, Stephen Doogan³, Nathan Artzt¹, Quanwu Zhang, PhD¹

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Background

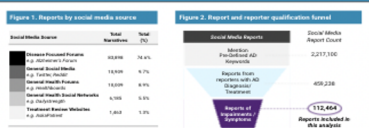
- Patients and caregivers living with Alzheimer's Disease (AD) are actively using online social media to garner support, ask or answer questions and/or discover new disease management strategies from others in similar situations.
- Across the different clinical severity stages of AD, patients and caregivers 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.
- 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.

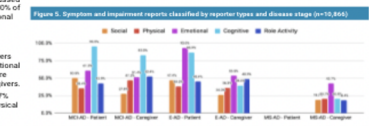
Methodology

- Online narratives were analyzed across 84 publicly available social media sources from January 1998 and December 2018 (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 Rytics Natural Language Processing (NLP) platform was used in combination with manual curation to analyze Social, Physical, Emotional, Cognitive, and Role Activity (SPEC-IR) 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.



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, 3,778 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 (86.9%), e.g. anxiety, depression and other emotional experiences. Cognitive issues followed, and were shared by 47.4% of patients and 45.4% 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.



Conclusion

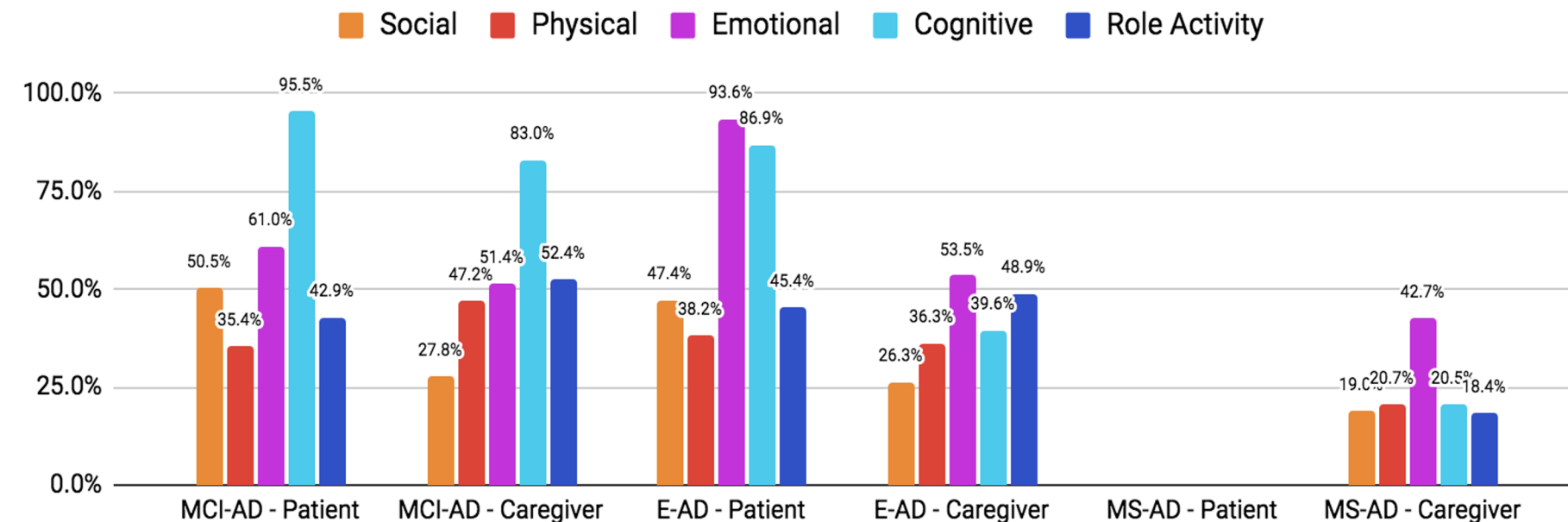
- Individuals with MCI-AD or E-AD were active on social media to share their experiences and challenges while those with MS-AD appeared to no longer participate in online communications relating to their illness. Caregivers were active on social media across disease severity stages.
- The frequencies 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

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

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.

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



- This social media study using NLP uncovers a broad range of challenges experienced by patients with AD and the caregivers during the COVID-19 pandemic. Given that in-person social interactions were limited during the pandemic, social media offered a valuable platform to capture real world feedback from a remote standpoint.
- Both patients and caregivers appear to have suffered unique health, cognitive, social, emotional, interpersonal, and daily living burden, resulting in worsening of disease and declining wellbeing. The untoward consequences may well likely surpass the pandemic, leading to prolonged deleterious impact in patient and caregiver personal lives and deepened public health crisis with AD.
- Subsequent analysis into the patient and caregiver experience following widespread vaccine rollouts would be useful to inform whether the issues identified in this study persist.

Understanding the Impact of COVID-19 Pandemic on Patients with Alzheimer's Disease and Caregivers Using Online Narratives On 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 engage with others in similar situations.
- The COVID-19 pandemic has disproportionately impacted individuals with pre-existing health conditions, notably amongst those requiring long-term care.
- For the safety of the patients and staff, many research activities such as interviewing or observing patients in-person ceased (1). Social media listening offered a unique opportunity to observe patient and caregiver narratives during the pandemic.

Objectives

- This study aims to describe the challenges of people with Alzheimer's disease (AD) and their caregivers experienced during the pandemic.
- Additionally, the study intends to gather narrative reports of disease progression after a COVID-19 diagnosis. These narrative reports are from caregivers and also patients.
- Lastly, the pandemic and associated shut-down orders have added to the burden of illness. To the best of our knowledge, these changes have not yet been studied. We investigate the reported changes in the burden of illness.

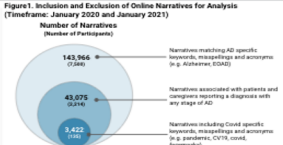
Methodology

We used the RNLite NLP (Natural Language Processing) platform to analyze key challenges and issues that were shared online over 47 social media sites by patients living with AD and caregivers during the COVID-19 pandemic between January 2020 and January 2021. A total of 3,422 narratives from 135 social media participants were included in the sample (121 caregivers and 14 patients).

No narratives were collected from password-protected sites and personally identifiable information was not collected. Any quasi-identifiers such as age were aggregated before inclusion in the dataset.

The narratives were collected from pre-existing, unguided, patient-led discussions. The geographical locations of the users included more than 10 countries. For each narrative, we collected data on the date, time, username, and text including discussion, thread title, and blog post title. Narratives were included in the sample based on a multi-stage filtering process based on a series of keywords (see Fig. 1).

Figure 1. Inclusion and Exclusion of Online Narratives for Analysis (Timeframe: January 2020 and January 2021)



Results

- The 3,422 narratives were analyzed and reported in aggregate categories, including extensive descriptions on the worsening of AD, difficulties in understanding and maintaining roles of masking and social distancing, limited opportunities of social interactions, reduced caregiver availability, and emotional disturbance or exacerbation with fear, anxiety, and loneliness.
- Disease worsening manifested with or without COVID-19 diagnosis, leading to increased reliance and need for caregiver assistance and declining patient wellbeing. The patient challenges were compounded by increased caregiver burden, expressed through the social media on disruptions to work-from-home routines and the need for additional caregiver support to sustain household income.
- The caregiver narratives revealed a range of challenges, including common issues of getting access to COVID-19 vaccines and unique issues of having to reminding or assisting patients with handwashing, social distancing, or staying at home. Patient disease progression resulting from restrictive caregiver access to long-term care facilities was frequently communicated online by the caregivers, highlighting increased caregiver emotional stress that led to anger, frustration, crying, loneliness, depression and emotional fatigue.
- Patient narratives showed a variety of concerns including availability of vaccines, emotional impacts of COVID, demands on caregivers, and isolation from loved ones.

Conclusion

- This social media study using NLP uncovers a broad range of challenges experienced by patients with AD and the caregivers during the COVID-19 pandemic. Given that in-person social interactions were limited during the pandemic, social media offered a valuable platform to capture real world feedback from a remote standpoint.
- Both patients and caregivers appear to have suffered unique health, cognitive, social, emotional, interpersonal, and daily living burden, resulting in worsening of disease and declining wellbeing. The untoward consequences may well likely surpass the pandemic, leading to prolonged deleterious impact in patient and caregiver personal lives and deepened public health crisis with AD.
- Subsequent analysis into the patient and caregiver experience following widespread vaccine rollouts would be useful to inform whether or not the issues identified in this study persist.

References

1) Alzheimer's Disease Research Enterprise in the Era of COVID-19/SARS-CoV-2. *Alzheimers Dement.* 2020;14(4):587-588. doi:10.1002/alz.12093
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7161893/>

Genetic Testing in Alzheimer's Disease: Concerns and Consequences

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¹Esai, Inc., New Jersey USA; ²Cognitive Neuroscience Division, Department of Neurology, College of Physicians and Surgeons, Columbia University, New York USA; ³Real Life Sciences, Inc., New York USA

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Objectives

- To gain insights about the genetic testing in AD from social media narratives posted by patient, caregiver, healthcare provider.

Background

- Increasingly, patients are opting for genetic testing for APOE-4 in Alzheimer's disease in the presymptomatic stage (1). However, patients may have concerns around genetic testing and also may need more information after the results are obtained. Social media has become a preferred mode of gaining information about genetics, genomics, and genetic disorders including rare diseases (2). A systematic study of social media narratives from patients with AD and their caregivers can provide further insights into the genetic testing in AD.

Methodology

- In this project, we used the Rlytics Natural Language Processing (NLP) platform and manual curation to aggregate and analyze social media narratives. These online narratives included in our search frequently reported issues experienced by patients, caregivers, and healthcare providers.
- The posts were extracted from AD-specific social media using the following search terms: "APOE" or "Genetic Testing". Additionally, we extracted posts from non-AD-specific social media properties using only the "APOE" search terms. "Genetic testing" would have returned too many non-APOE related posts. Rlytics uses syntactic/relational concept models to classify the ways in which medical conditions and functions are reported in real text. These terms and their relationships with each other, in particular diagnosis relation, function impairment relation, were analyzed using the NLP platform.

Results

The total number of posts included in this analysis was 2,723. These posts were made by 1,049 total unique reporters. A total of 21 themes were extracted from the narratives. From further analyses of these themes, five main categories emerged and overall conversations around APOE testing can be summarized in these five categories:

- 1) Patients and caregivers seeking support and education - narrators needed more information to understand the test applicability/usefulness/validity. The validity of the test for early-onset AD was questioned. Also, they wanted to understand the testing rationale. Narrators wondered if testing could help explain unexplained neuro-symptomatology, testing characteristics/approaches. Narrators were confused with HCP recommendations against testing or genetic counseling. They sought additional patient support post-test results.
- 2) Access concerns - narrators expressed concern around access to testing issues such as cost of testing, location or lab, and physician or personnel. High costs (~\$8000) were a barrier to conduct the test. Narrators also had employment concerns such as workplace harassment or job loss after test results.
- 3) Emotional impact of results on self and family - narrators expressed emotional concerns such as they need to prepare for a positive diagnosis. They also indicated emotional relief upon receiving negative test results. Narrators with familial Alzheimer's disease were concerned about childbearing or child inheritance.
- 4) Concerns around privacy of the results impact on insurance coverage or employment - narrators expressed concern about their genetic information being sold to insurance companies, resulting in underwriting insurance coverage or any other financial product that had pre-existing condition clauses.
- 5) General uncertainty on what the next steps would be after receiving results - narrators were worried about the urgency for testing and their managing positive results. They were curious about support groups specific for mild cognitive impairment. Narrators were not sure about presymptomatic AD testing given their positive test results, participating in clinical trials for genetic testing. These narratives highlight a need for a patient-centered care and support system.

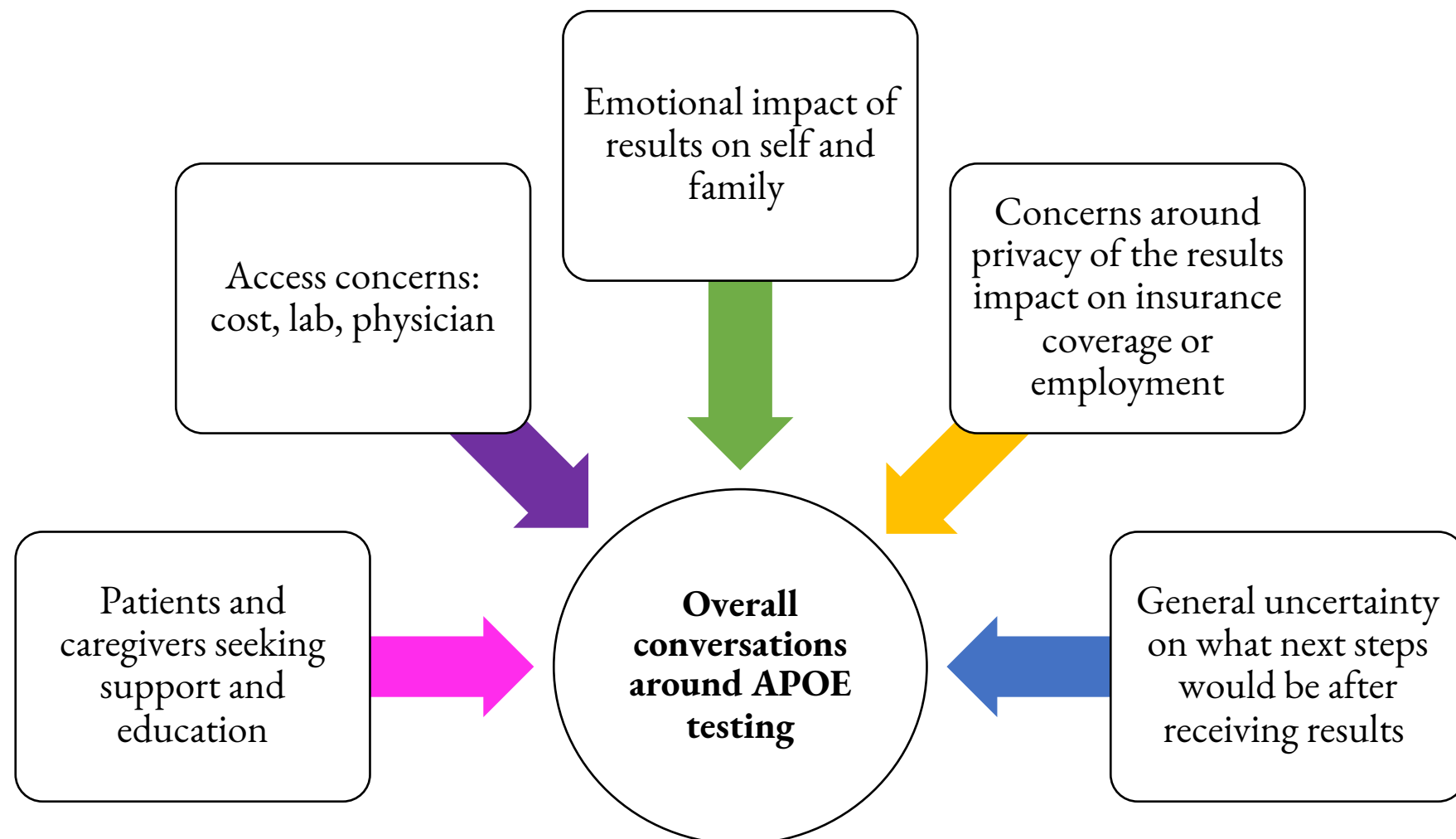
On this more detail around patients vs caregivers vs topic results

Conclusion

Genetic testing for APOE-4 for probable AD is a widely discussed topic on social media. Social media narratives posted by patients, caregivers, healthcare providers include a wide range of positive and negative issues around genetic testing in AD. These issues include concerns about the testing itself and concerns around the consequences of testing. Using NLP, these social media narratives can provide us actionable insights that are useful in delivering patient-centered care.

References

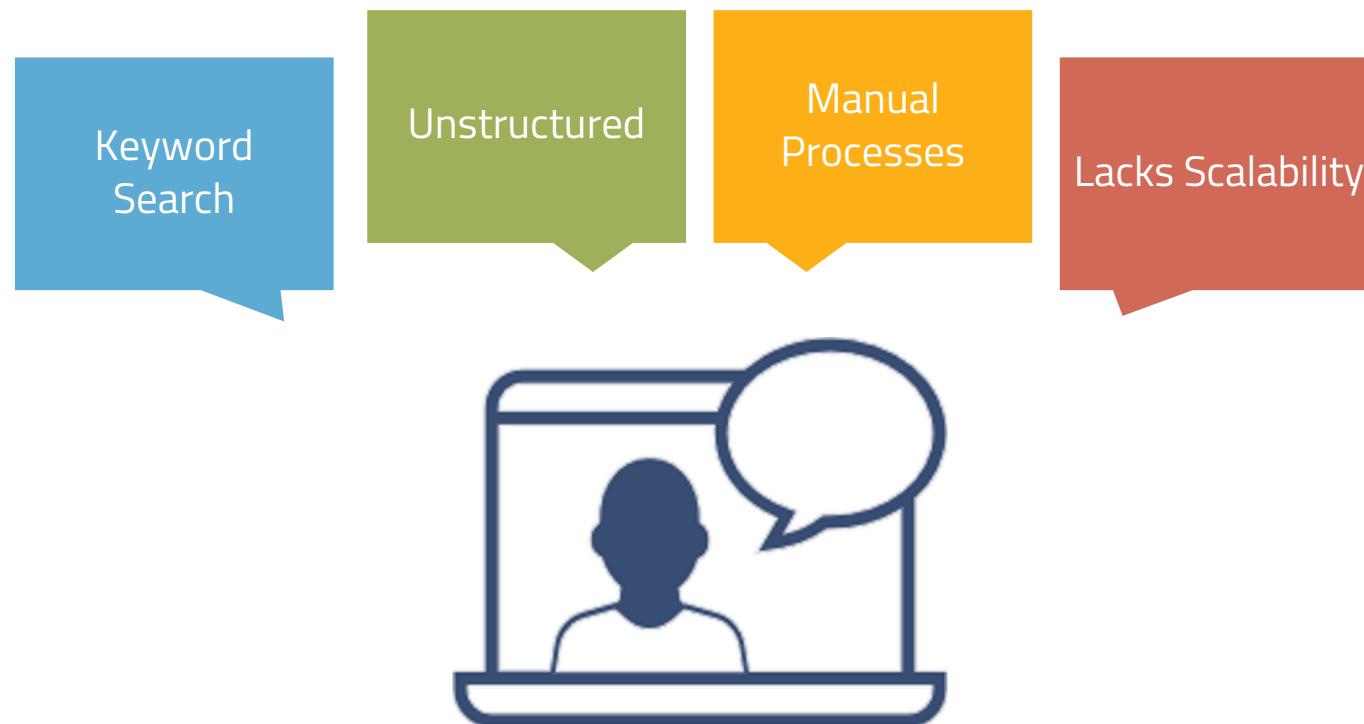
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2. Alter CL, Anderson B, Khoury MJ, Roberts MC. Current Social Media Conversations about Genetics and Genomics in Health: A Twitter-Based Analysis. *Public Health Genomics*. 2018;21(1):29-39. doi:10.1159/000494381





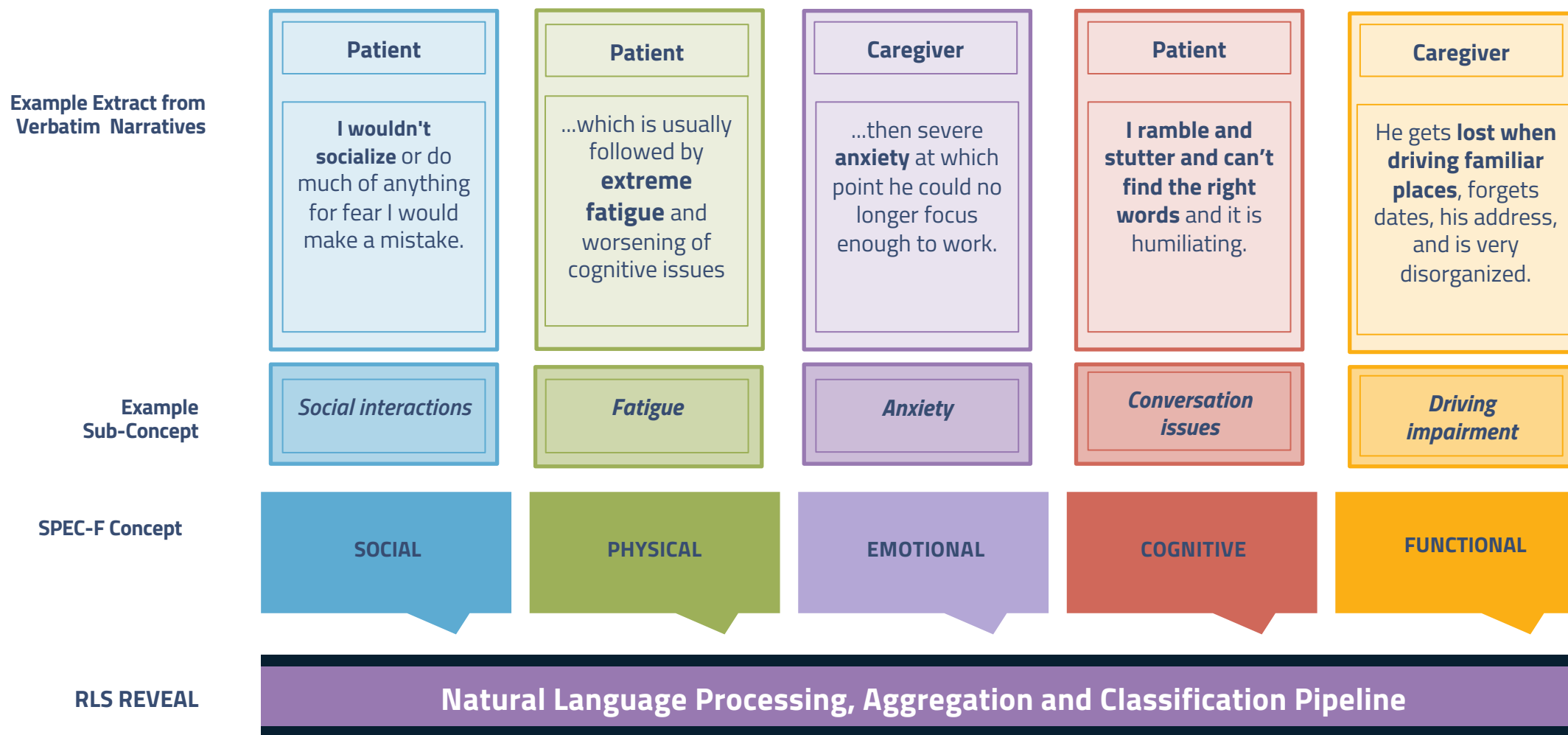
How does Social Media Epidemiology Work?

**Social Media Listening
alone lacks the
sophistication to provide
meaningful insights to
patient perspectives**



Data Sources used for RLS Reveal

Social Media	Spontaneous Reporting	Medical Information	MSL CRMs	CIOMS	Published Literature	Patient Surveys	CSRs	EHRs / EMRs
Population Metrics	Population Characteristics	Disease and Lifestyle Outcomes	Treatment Outcomes	Healthcare Outcomes				
- Anonymized Patient Profiles - Demographic Segmentations - Location Mapping and Geographic Profiling	- Patient Subtyping and Stratification - Comorbidities - Concomitant Treatments	- SPECF Symptom and Impairment Modeling - Social - Physical - Emotional - Cognitive - Functional	- Treatment Efficacy and Tolerability Modeling - Treatment Adoption, Attrition and Switching - Adverse Event Monitoring and Signal Detection	- HCP and Care Team Mapping and Modeling - HCP Perception, Experience and Decision Modeling				



Discovery / Development

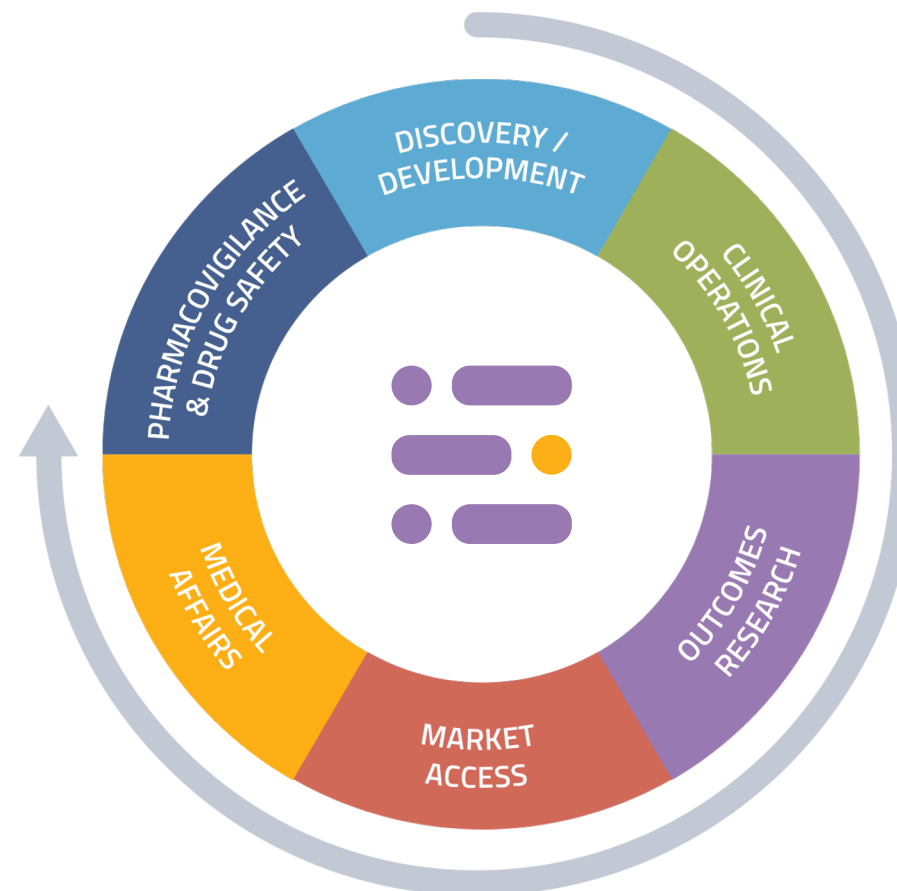
- Indication Selection and Prioritization
 - Treatment Unmet Needs
 - Target Product Profile (TPP)
- Development

Medical Affairs

- Medical Plan Development
- Scientific Publication and Evidence Generation
- HCP/KOL Mapping and Modeling

Pharmacovigilance & Drug Safety

- Adverse Event Extraction and Classification
- RWD Signal Detection



Clinical Operations

- Study and Protocol Design
- Endpoint Selection and Prioritization
- Site/Subject Recruitment Planning

Outcomes Research

- Outcome Assessment and Survey Design
- PROM/COA Design and Evaluation
- New Instrument Development

Market Access

- Value Dossier Development
- Burden of Illness Assessment
- Patient-Centered Evidence Gap Analysis

Enhance critical decision making with Social Media Epidemiology

Refined evidence
generation,
strategy, and
design

Increase volume
and variety of data
on a platform

Help developing
shortlists of novel
PRO endpoints

Refined HCP, payer
and patient
engagement
strategies

Dig deeper into
patient journey of
diseases and
treatments



Thank you

If you have any questions email me at
nfarid@rlsciences.com