

# Cognitive and Mental Health Challenges in Fabry Disease: A Real-World Evidence Study Using Social Media

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Words: 300 (300 max)

To comprehensively understand the impact of a disease on a patient's emotional and mental health, it is necessary to listen to and interpret the patient perspective. Fabry disease has been associated with reduced cognitive functioning and mental health challenges, but the specific cognitive challenges associated with Fabry disease and how they relate to mental health outcomes are not fully known.

Here, we aimed to identify the most prevalent cognitive challenges in online Fabry communities. As a secondary aim, we explored associations between these cognitive difficulties and specific mental health symptoms.

A proprietary natural language processing engine analyzed 158,000+ posts/comments from a private Facebook group (Fabry's Disease Info and Support) and 2 subreddits (r/fabry, r/fabrysdisease) from 2007 to 2023. This engine uses clinical entity recognition to extract symptoms, medications, and other medical terminology from social media conversations. 'Fatigue' and 'brain fog' were the most frequent cognition-associated symptoms across Fabry communities, ranking as the 2nd and 11th most mentioned symptoms overall, respectively. Posts/comments mentioning 'fatigue' and 'brain fog' were used for continued analysis. The engine then identified 'depression' as the most frequently occurring mental/behavioral dysfunction in each group. 'Depression' mentions were significantly associated with both 'brain fog' and 'fatigue' mentions, with the 95% CIs for the odds ratios being 2.64 to 7.33 and 2.92 to 5.55, respectively. This suggests that the odds that a post/comment mentions 'depression' is 2 to 7 times higher for documents that mention 'brain fog' or 'fatigue' than for documents mentioning other symptoms.

These findings illustrate the potential impact of cognitive challenges in the Fabry community, both for patients' ability to perform daily tasks and possible broader implications for mental health and quality of life. More research is needed to understand the role of cognitive difficulties in Fabry disease to inform clinicians and support patients in their journey.

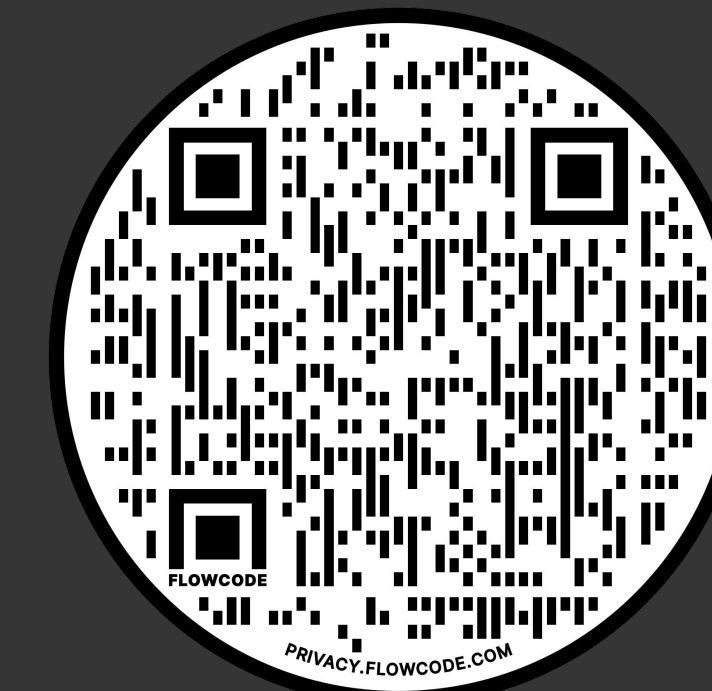


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## BACKGROUND

To understand the impact of a disease on a patient's emotional and mental health, it is necessary to listen to and interpret the patient perspective.

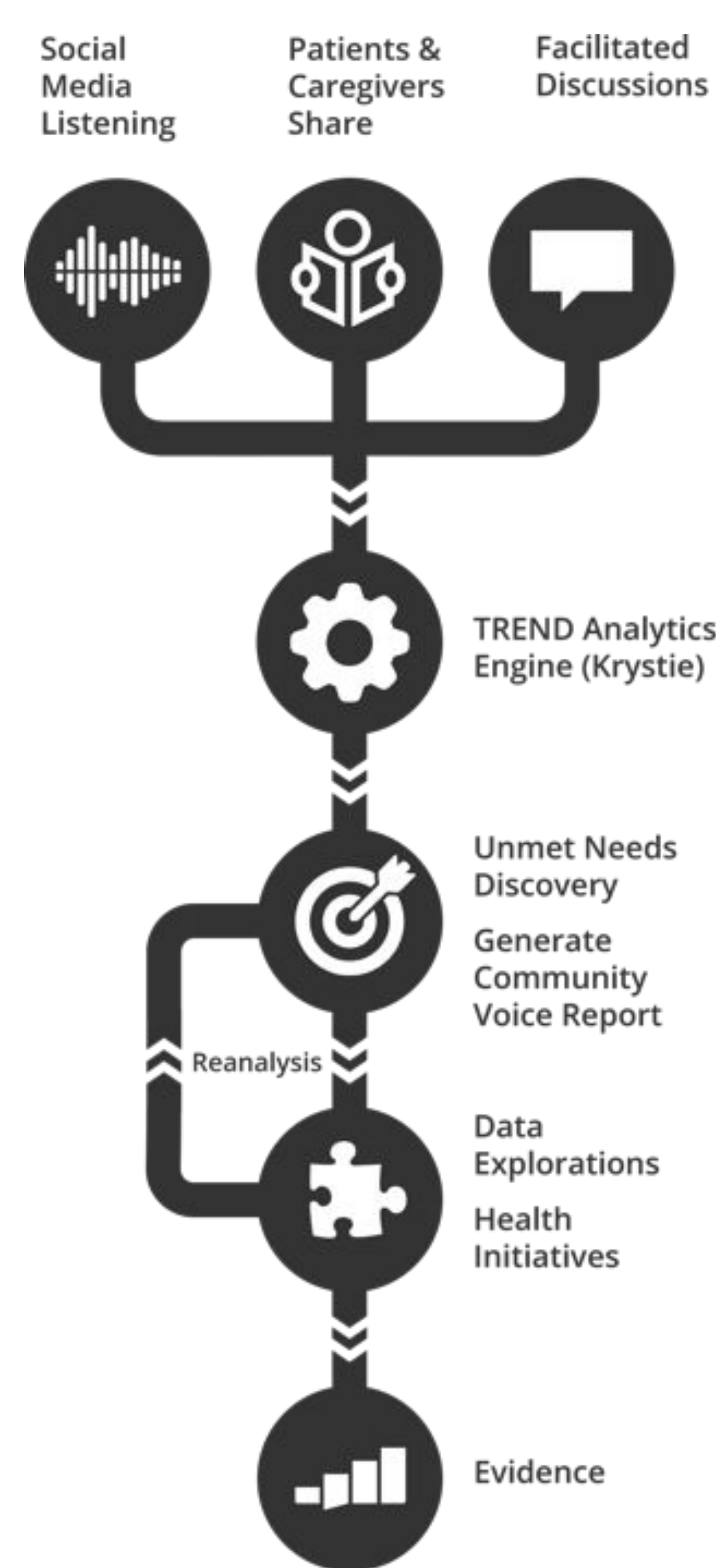
Fabry disease has been associated with reduced cognitive functioning<sup>1</sup> and mental health challenges.<sup>2</sup>

The specific cognitive challenges associated with Fabry disease and how they relate to mental health outcomes are not fully known.

Here, we aimed to identify the most prevalent cognitive challenges in online Fabry communities. As a secondary aim, we explored associations between these cognitive difficulties and specific mental health symptoms.

## METHODS

Figure 1. The TREND Approach



We evaluated 2 online social media communities: a private Facebook group and a public subreddit.

These groups were analyzed using a proprietary analytics engine, *Krystie* (Fig. 1), which extracts and evaluates social media conversations using natural language processing.

*Krystie* uses clinical entity recognition to identify medical terminology discussed on social media. This results in a targeted extraction of symptoms, medications, mental and emotional terms, and other clinical categories.

This analysis focused on identifying the most prevalent cognition-associated symptoms and relating them to emotional and mental health.

## RESULTS

Data sources for this analysis included a private Facebook group, *Fabry Disease Info and Support*, and a public subreddit, *r/fabrydisease*. The details for each group are presented in Figure 2. More than 157,000 posts/comments over 10+ years were analyzed.

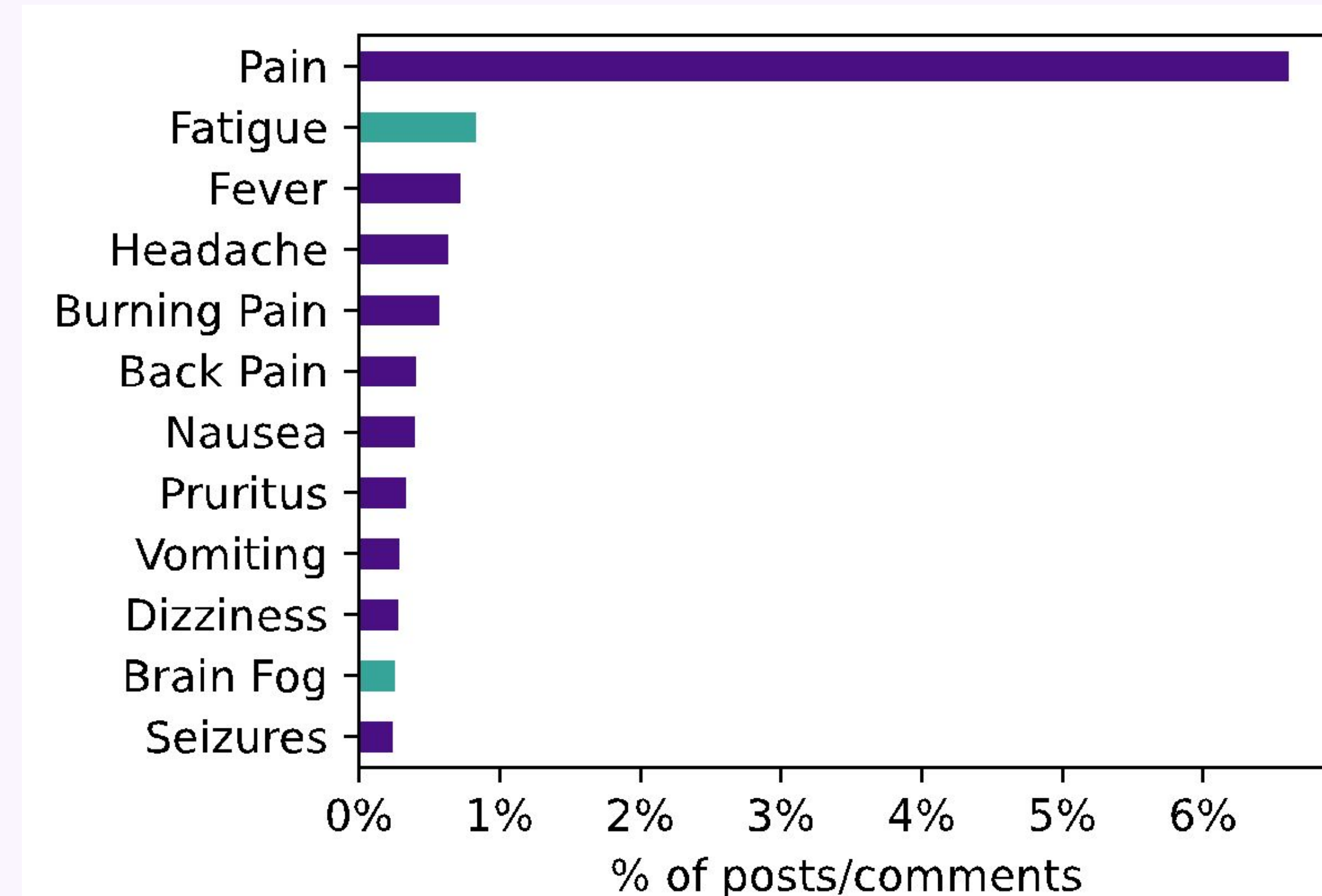
Figure 2. Data Sources

<b>FACEBOOK:</b>	<i>Fabry Disease Info and Support</i>	157,000+ POSTS & COMMENTS	2007-2021 DATE RANGE
<b>REDDIT:</b>	<i>r/fabrydisease</i>	350+ POSTS & COMMENTS	2013-2023 DATE RANGE

The most frequently mentioned symptoms across the 2 communities are presented in Figure 3. The most frequently mentioned symptom was *pain*, occurring in 6.6% (10,459) of all posts/comments.

The 2 most frequent symptoms associated with cognition included *fatigue* (0.8% [1,313 posts/comments]) and *brain fog* (0.2% [398 posts/comments]). Continued analyses focused on *fatigue* and *brain fog* conversations.

Figure 3. Top Symptoms Mentioned in Online Fabry Communities



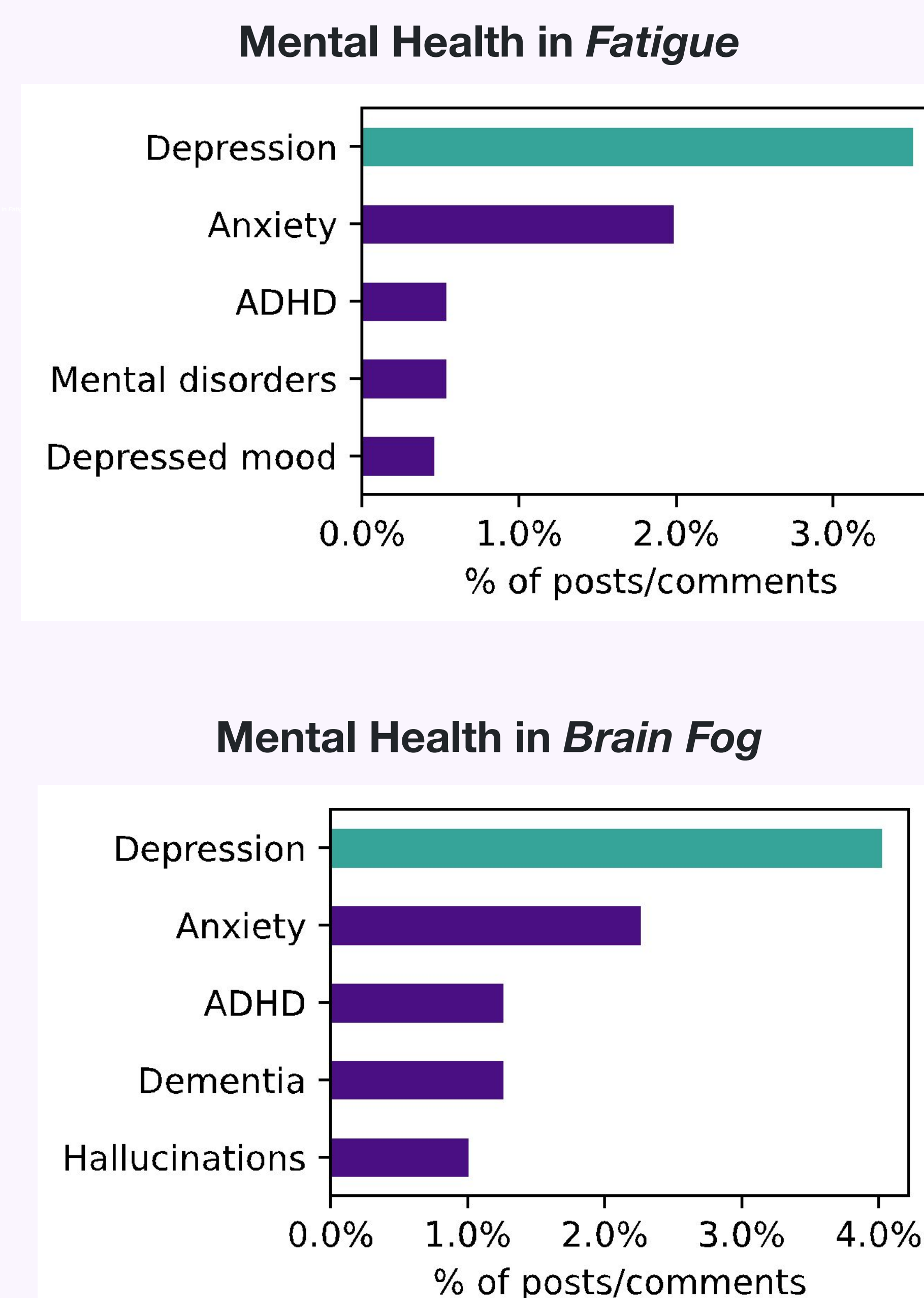
To understand the impacts of cognitive challenges on mental and emotional health, we explored the most frequent mental/behavioral issues discussed in both *fatigue* and *brain fog* conversations.

*Depression* was the most discussed mental/behavioral issue in both groups. Figure 4 shows the top mental/behavioral issues discussed by group.

In *fatigue* conversations, *depression* was mentioned in 3.5% of posts/comments. In *brain fog* conversations, *depression* was mentioned in 4.0% of posts/comments.

*Depression* mentions were significantly associated with both *fatigue* and *brain fog* mentions, with odds ratios (95% CIs) between 2.92 to 5.55 and 2.64 to 7.33, respectively; this suggests the odds that a post/comment mentions *depression* is approximately 2 to 7 times higher for posts/comments that mention *fatigue* or *brain fog* than for posts/comments mentioning other symptoms.

Figure 4. Top Mental Health Symptoms in *Fatigue* and *Brain Fog* Conversations



## CONCLUSION



This analysis explored cognitive symptoms across 2 social media sources dedicated to Fabry disease.

The most frequently discussed symptoms that relate to cognition included *fatigue* and *brain fog*. Mentions of both *fatigue* and *brain fog* were significantly associated with *depression* mentions.

Although pain has been associated with depression in previous research,<sup>2</sup> this work highlights the potential role of cognitive challenges in exacerbating depression and other negative mental health symptoms.

These findings illustrate the potential impact of cognitive challenges in the Fabry community, both for patients' ability to perform daily tasks and the possible broader implications for mental health and quality of life.

Future work is required to understand the role of cognitive difficulties in Fabry disease to inform clinicians and support patients in their journey.

## REFERENCES

1. Sigmundsdottir L, Tchan MC, Knopman AA, Menzies GC, Batchelor J, Sillence DO. Cognitive and psychological functioning in Fabry disease. *Arch Clin Neuropsychol*. 2014;29(7):642-650. doi:10.1093/arclin/acu047
2. Mroczek M, Maniscalco I, Sendel M, Baron R, Seifritz E, Nowak A. Neuropsychiatric symptoms and their association with sex, age, and enzyme replacement therapy in Fabry disease: a systematic review. *Front Psychiatry*. 2022;13:829128. doi:10.3389/fpsy.2022.829128