

Introduction

- Neuromyelitis optica spectrum disorder (NMOSD) is a rare CNS autoimmune disease
- Immune-mediated processes damage astrocytes in the optic nerve and spinal cord, leading to demyelination and neuronal cell death (Patterson & Goglin, 2017)
- Inflammatory attacks result in lesions throughout the optic nerves and spinal cord, causing debilitating central neuropathic pain
- Patients with NMOSD report little relief from pain medication (Qian et al., 2012)
- Currently, there are no effective pain intervention methods
- Severe and pervasive leads to diminished quality of life

Aims

- The objective of this investigation is to examine the relationship between pain and quality of life in patients with NMOSD, and to evaluate how the relationship is mediated by other critical lifestyle factors, specifically, anxiety, sleep disturbance, and depression.

Methods

- Patients are currently being recruited from the Neuromyelitis Optica Spectrum Disorder Clinic at Johns Hopkins University or via NMOSD support groups on social media
- 100 participants are being recruited, 64 have completed the study
- Recruitment procedures**
 - Patients are introduced to the research opportunity while receiving treatment at the NMOSD clinic at Johns Hopkins University or via NMO support groups on social media
 - Patients outside of the NMOSD Clinic at Johns Hopkins must undergo phone or email based eligibility screening by the research team
 - Patients interested in participating can contact the research team and the research team provides thorough education on the informed consent
- Eligibility criteria**
 - Inclusion Criteria:
 - Patient ≥ 18 years-old
 - Diagnosis of NMOSD based on the 2015 international consensus diagnostic criteria (Wingerchuk et al., 2015)

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Measures

- Measures were completed in-person, over the phone, or by email depending on the participant's visual impairment and capabilities

Patient self-report

- Pain: Brief Pain Inventory
- Anxiety: Neuro-QOL Anxiety
- Depression: Neuro-QOL Depression
- Sleep: Neuro-QOL Sleep Disturbance
- Health Survey: SF-36 Questionnaire

Participants

Table 1. Demographics (n = 64)

Characteristic	Frequency(n)/Mean(SD)
<i>Patient</i>	
Female	74% (48)
Male	26% (16)
Age (years)	52.98 (11.086)
Age at Onset (years)	43.85 (13.77)
Disease Duration (years)	9.12 (8.509)
Delay in Diagnosis (years)	2.97 (5.87)

Results

Table 2. Descriptive Statistics for Quality of Life Measures and Pain

Measure	Mean	SD
Depression: Neuro-QOL Depression	14.84	6.03
Anxiety: Neuro-QOL Anxiety	18.95	6.56
Sleep Disturbance: Neuro-QOL Sleep	19.61	6.29
Pain Severity: Brief Pain Inventory	3.71	2.40
Pain Interference: Brief Pain Inventory	3.81	2.84
Health Survey: SF-36 Questionnaires	47.22	19.18

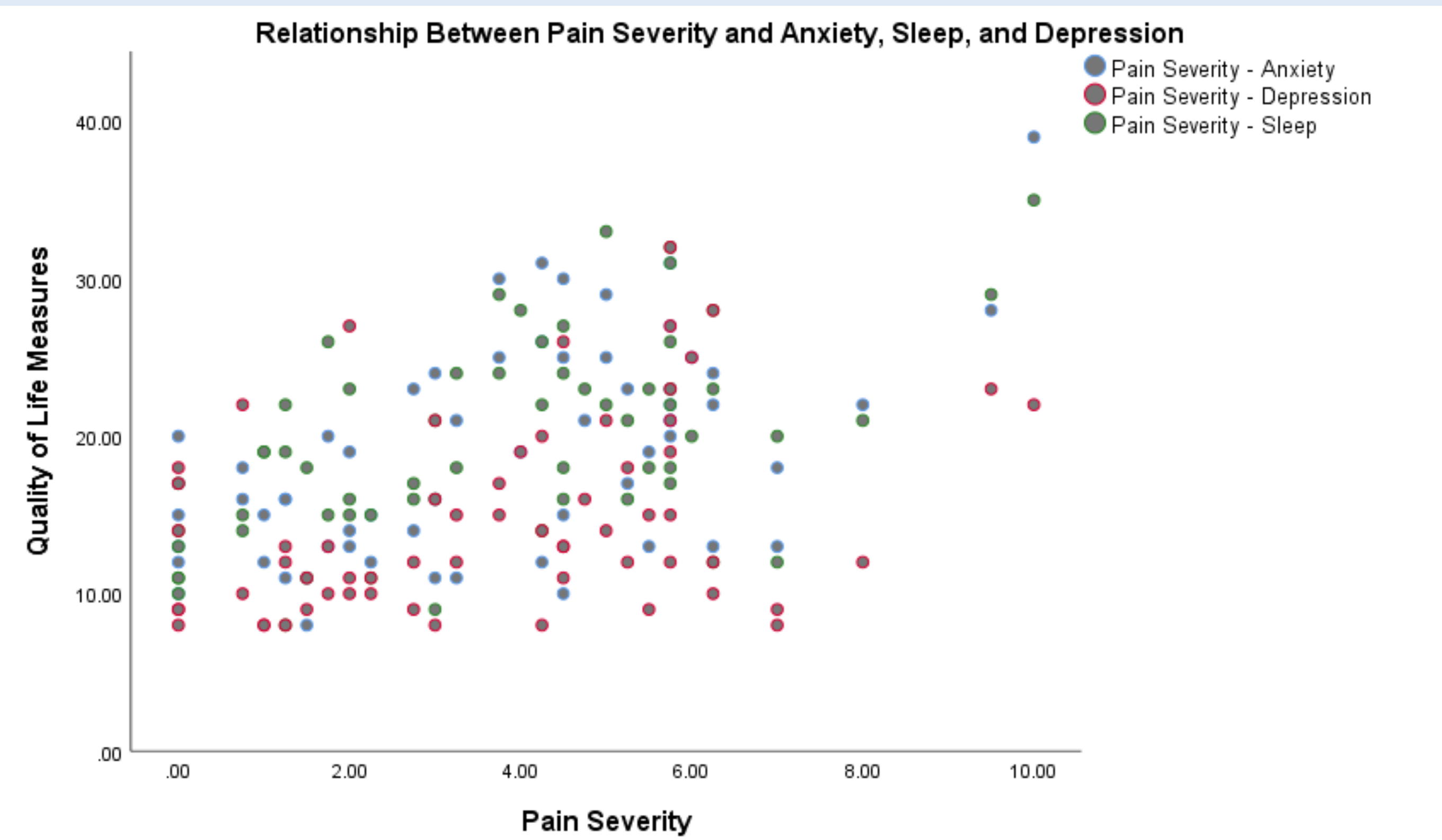
Table 3. Associations of Psychosocial Variables and Feeding Styles

	Pain Severity	Pain Interference	Self-Report Health Survey
Anxiety	.570**	.634**	-.529**
Sleep	.559**	.672**	-.588**
Depression	.373**	.446**	.493**

** Correlation is significant at the 0.01 level

Results

Graph 1. Quality of Life Measures Compared to Self-Reported Pain



Conclusions

- Preliminary data suggests that the factors anxiety, depression, and sleep disturbance are closely related to self-reported pain and beliefs about overall health.
- While a strong correlation was expected, as these factors are closely related, this data suggests that pain is more controlled or less severe than expected. That being said, a larger sample size and more extensive analysis is necessary to make conclusions about the severity of pain levels.
- Upon completion of data collection, we will determine the relationship between pain (BPI) and quality of life, and how that relationship is mediated by other co-occurring symptoms (factors measured by the Neuro-Qol Short Forms).
- With further investigation, the expectation is to find that pain is a major component of quality of life. This reinforces the need for investigating high quality pain intervention methods for those suffering with NMOSD.

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