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Quality of Life in Patients With Neuromyelitis Optica

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Introduction

Neuromyelitis optica spectrum disorder (NMOSD) is a rare autoimmune disease of the central nervous system. While the underlying pathophysiology of NMOSD is not fully understood, research indicates that immune-mediated processes target astrocytes in the optic nerve and spinal cord, leading to cell damage, demyelination, and neuronal cell death (Patterson & Goglin, 2017). The inflammatory attacks result in lesions throughout the optic nerves and spinal cord, often causing debilitating central neuropathic pain. Central neuropathic pain associated with NMOSD is severe and pervasive. Unfortunately, patients with NMOSD report little relief from pain medication. In fact, medications that significantly help relieve pain in patients with multiple sclerosis, another disease that causes recurrent inflammation in the CNS, do not significantly help relieve pain in NMOSD (Qian, Alvarez, Klawiter, Cross, & Naismith, 2012). Despite use of multiple prescription pain medications, pain associated with NMOSD is uncontrolled, severe, and greatly impacts quality of life. While existing discourse illuminates that patients with NMOSD experience severe pain, there is a gap in the literature evaluating how quality of life and pain are mediated by other critical lifestyle factors. Specifically, anxiety, sleep disturbance, and depression are all correlated with quality of life (Hollinger et al., 2016; Moore et al., 2015; Shi et al., 2016). By accounting for these variables, we hope to more fully understand the relationship between pain and quality of life, which may allow for more meaningful investigation of evidence-guided interventions that impact quality of life in the future.

Methods

One hundred patients are currently being recruited from the Neuromyelitis Optica Spectrum Disorder Clinic at Johns Hopkins University. The patient must be > 18 years old with a diagnosis of NMOSD based on the 2015 international consensus diagnostic criteria (Wingerchuk et al., 2015). While this study is investigating pain and quality of life, all patients meeting the inclusion criteria, regardless of pain level, are eligible to participate. To date, 36 participants have completed the study. Of the 36 participants, 32 are female and 4 are male, with over 50% of the sample identifying as caucasian. On average, disease duration is about 8 years long, with the average age of onset at about 45 years old. From the time of symptom onset, 2.9 years typically elapsed until receiving the diagnosis of NMOSD.

Eligible participants are introduced to the study by their physician during their scheduled clinic appointment or are contacted by email. Interested participants are taken through informed consent, and if they agree to participate, they complete 5 surveys including the Brief Pain Inventory, Neuro-QOL Anxiety, Neuro-QOL Depression, Neuro-QOL Sleep Disturbance, and SF-36 Questionnaire. These surveys are administered in-person, over the phone, or by email depending on the participant's visual impairment and capabilities. To reduce risk of loss of confidentiality, the researchers have strict de-identifying protocols in place to protect the confidentiality of the participants. When a participant is enrolled in the study, they are assigned an alpha -numeric code. The participant enters their assigned alpha -numeric code at the top of each online survey, which then allows the researchers to sort the data by participant identifier, without knowing each individual's identity. These data are on a password-protected spreadsheet, along with demographic and clinical data extracted from the medical records. Data collection is ongoing. Upon

completing data collection, the researchers will run descriptive analysis on demographic information, and conduct multiple regression tests and correlations to understand the relationship between tested variables. The goal of the analyses is to evaluate how quality of life and pain are impacted when controlling for variables like anxiety, depression, or sleep.

Results

Data collection is ongoing but preliminary descriptive statistics have been calculated. Thirty six patients with NMOSD have completed the study to date. Most patients were female (86%) and Caucasian (74%). Mean age at enrollment was 53.8 years (SD 11.3) and disease duration was a mean 8.5 years (SD 8.0).

Raw scores collected for each of the Neuro QOL surveys were converted into T-scores for each participant, which allows for standardization across surveys. T-scores for the general population on each of the Neuro QOL forms result in a mean (M) of 50 and a standard deviation (SD) of 10. For the current study, results indicate M = 48.64, SD = 7.36 on the Neuro QOL Depression survey. On the Neuro QOL Sleep Disturbance survey, results indicate M = 52.82, SD = 9.48. On the Neuro QOL Anxiety form, results indicate M = 53.59, SD = 6.34. When data collection is complete, multiple regression tests and correlations will be utilized to evaluate relationships between the data and test for clinical significance.

Discussion

Based on current descriptive statistics, means and standard deviations fall relatively close to population averages. That being said, further testing and a larger sample size is required to evaluate statistical significance.

Title:
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Keywords:
Neuromyelitis Optica, Pain and Quality of life

References:
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Abstract Summary:
Neuromyelitis optica spectrum disorder is a rare CNS autoimmune disease, resulting in lesions throughout the optic nerves and spinal cord. NMOSD causes profound disability and severe central neuropathic pain. This study evaluates pain and quality of life, and how the relationship is mediated through depression, anxiety, and sleep disturbance.

Content Outline:
Introduction

- What is neuromyelitis optica spectrum disorder (NMOSD)?
    - NMOSD is a rare autoimmune disease of the central nervous system
    - Pathophysiology is not fully understood, but research indicates immune-mediated processes target astrocytes in the optic nerve and spinal cord, leading to cell damage, demyelination, and neuronal cell death (Patterson & Goglin, 2017)
    - The inflammatory attacks result in lesions throughout the optic nerves and spinal cord, often causing debilitating central neuropathic pain
- How does the disease cause severe pain and profound disability?
    - Lesions throughout the optic nerves and spinal cord cause debilitating central neuropathic pain
    - Central neuropathic pain associated with NMOSD is severe and pervasive
    - Patients with NMOSD report little relief from pain medication
    - Medications that significantly help relieve pain in patients with multiple sclerosis, another disease that causes recurrent inflammation in the CNS, do not help relieve pain in patients with NMO (Qian, Alvarez, Klawiter, Cross, & Naismith, 2012)
    - Pain impacts quality of life

Body

Main point #1- How the relationship between pain and quality of life could be mediated by other factors, such as depression, anxiety, and sleep disturbance

- Gap in the literature evaluating how quality of life and pain are mediated by other critical lifestyle factors.
    - Anxiety, sleep disturbance, and depression are all correlated with quality of life (Hollinger et al., 2016; Shi et al., 2016; Moore et al., 2015).
    - By accounting for these variables, we hope to more fully understand the relationship between pain and quality of life, which may allow for more meaningful investigation of evidence-guided interventions that impact quality of life in the future.

Main point #2 - What do the results of the study tell us about the relationship between pain and quality of life

- Data collection is ongoing but preliminary descriptive statistics have been calculated
- Thirty six patients with NMOSD have completed the study to date
- When data collection is complete, multiple regression tests and correlations will be utilized to evaluate relationships between the data and test for clinical significance

Conclusion- What are the clinical applications of the results of this study?

- Because data collection is ongoing, this question cannot be answered yet
- The goal of this study is to understand more about how pain and quality of life interact, and how understanding this can help inform research and clinical care of NMOSD patient

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Professional Experience: 2013-2017, B.S. in Psychology at Denison University, Researched Perinatal Mood and Anxiety Disorders 2017-2019, MSN Candidate at Johns Hopkins University School of Nursing, Researching NMOSD
Author Summary: Lauren Totonis is a MSN Candidate in the Master's Entry program at Johns Hopkins School of Nursing. After her first semester, she was accepted into the Research Honors Program, which allowed her to pursue research in neurology. Lauren joined a team of researchers investigating neuromyelitis optica spectrum disorder (NMOSD), a rare autoimmune neuroinflammatory condition. Lauren is interested in pursuing a career in nursing research.

Second Author
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Professional Experience: Published peer-reviewed original science research in Neurology, JAMA Neurology, and Multiple Sclerosis Journal Presented research at the annual conference of the American Academy of Neurology in 2011, 2013, 2014, 2015, and 2016 Member of STTI.
Author Summary: Maureen A. Mealy has longstanding experience in neurosciences at Johns Hopkins, having begun her nursing career in the Neurosciences Critical Care Unit. She later joined the Johns Hopkins Multiple Sclerosis, Transverse Myelitis (TM), and Encephalitis Centers in January of 2007 as the Senior Research and Clinical Nurse. In 2010, she became the Program Manager of the Johns Hopkins TM Center and Neuromyelitis Optica (NMO) Clinic.

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Professional Experience: 2009-present: Assistant Professor, Johns Hopkins University, School of Nursing. I completed post-doctoral training in biobehavioral pain research (2006 - 2009) at the Johns Hopkins University, where I obtained NIH funding to conduct rodent studies of pain and sleep disturbance during paclitaxel therapy (supported through K01 NR011321, Oncology Nursing Society Foundation, and The Lucille V. Lukens, RN Award from the American Nurses Foundation).

Author Summary: Sharon Kozachik's research focuses on the relationship between pain and disturbed sleep and the mechanisms that underlie their co-occurrence. Dr. Kozachik is committed to relieving suffering through scientific exploration of the clinical phenomena that she observed as a clinician. She currently conducts bedside-to-bench translational research to determine: 1) the antecedents and consequences of pain and sleep disturbance, 2) whether alterations in HPA axis responsivity serve as a mechanism linking sleep disruption to increases in pain.

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Author Summary: Dr. Levy is focused on understanding the immunopathogenesis of neuromyelitis optica spectrum disorder (NMOSD), a rare autoimmune neuroinflammatory condition that leads to blindness and paralysis. In June 2009, he started the Neuromyelitis Optica Clinic (NMO) at Johns Hopkins to focus on the specialized diagnosis and treatment of NMO patients. In addition to clinical care, the center has conducted three investigator-initiated trials and is currently participating in three sponsored trials in NMO.