

SRF | 2025

# SHARING, UNDERSTANDING, AND EXCHANGING PERSPECTIVES

AN AUTOETHNOGRAPHIC JOURNEY THROUGH  
CHRONIC ILLNESS, DIAGNOSIS, AND THE DIALOGUES  
OF PATIENT / DOCTOR RELATIONSHIPS

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# INTRODUCTION



For over 12 years, I endured chronic pain, misdiagnosis, and medical gaslighting. My personal journey led to the discovery of rare vascular compression syndromes, including MALS (Median Arcuate Ligament Syndrome) and NCS (Nutcracker Syndrome). This experience sparked a passion to help others who face similar challenges, through the field of Communication Studies. Through my research and autoethnography, I discovered that my story is not isolated, and many others have struggled with the same issues.

The purpose of this work is to raise awareness about rare vascular compression syndromes, the dangers of medical gaslighting, and the importance of accurate, early diagnosis. By advocating for better understanding and empathy, I aim to improve patient outcomes and encourage more comprehensive care for complex medical conditions.

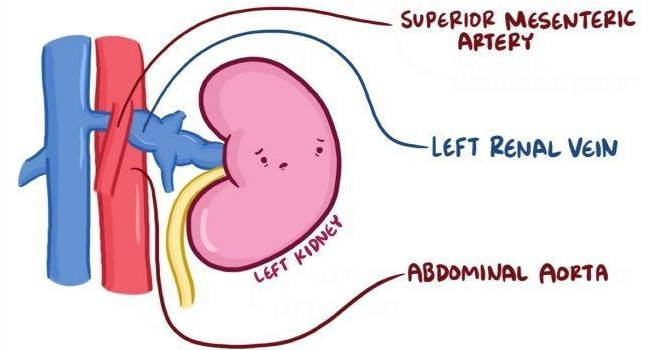
# VASCULAR COMPRESSION SYNDROMES:

Vascular Compression Syndromes are **rare and chronic conditions that occur when a person's blood vessels are under abnormal pressure**, which limits the size of the vessel and the amount of blood that can flow through it. (Nagarsheth, n.d., para. 3).

Differences in the clinical manifestations across patients make these conditions **rare and hard to diagnose**. While one patient with Nutcracker Syndrome (NCS) might experience as their main symptom extreme nausea and fatigue after eating, another might experience hematuria (blood in the urine), flank pain, or bloating.

Unfortunately, patients who suffer from vascular compression syndromes are commonly **dismissed and misdiagnosed** which can result in years of **physical pain, frustration, and emotional suffering**.

## RENAL NUTCRACKER SYNDROME



# PREVIOUS LITERATURE

**Medical Gaslighting:** "the act of a healthcare provider dismissing or ignoring a patient's concerns or complaints and leaving them without a clear treatment plan or diagnosis, often stating that the patient has an unspecified mental illness or is exhibiting an unnecessary amount of caution."

Illana Jacqueline, in her book 'Medical Gaslighting: How to Get the Care You Deserve in a System that Makes You Fight for Your Life'

Previous research is limited, however, research on communicative disenfranchisement and dismissal experience by female patients with **chronic overlapping pain conditions** (conditions similar to vascular compression syndromes in which medical professionals are **"not uniformly knowledgeable about the disease nor uniformly unbiased in their attitudes toward those who need care"**) do exist.

According to previous literature that draws from qualitative research on patients' negative experiences with their medical providers, common terms used by patients to describe how they felt their providers communicated the "realness" of their reported symptoms were **"dismissed" and "disbelieved"** (p.1). Burke (2019, p. 1) calls this phenomenon of disenfranchisement **"medicine's silent epidemic."**

(Hintz & Tucker, 2023) (Burke, 2019)

# AUTOETHNOGRAPHY

**A form of academic writing that combines personal narrative with analytical reflection. This approach allowed me to connect my health journey to the broader contexts in which this journey takes place. Autoethnography facilitates examining how emotions, values, and social structures shape personal and collective realities. (Chang, 2008; cf. Snyder, 2015), (Ellis et. al, 2010).**

“I can still recall that initial pain: a sudden, jarring sensation that forced me to slow down, my breath quickening as I struggled to push through the discomfort. I eventually fell to the ground, and I vividly remember seeing my dad run over to pick me up.”

“My jaw dropped. As I scrolled through numerous websites with lists of symptoms that those experiencing this illness face, I felt as though I was looking through a mirror into my own medical record. Now, what can I do to get a doctor to help me, I wondered.”

“I begin to cry. “Finally!” I exclaim. My many prayers have been answered, although I know that this is only the beginning of a long and arduous journey. The diagnosis of median arcuate ligament syndrome (MALS) and this new thing called Nutcracker Syndrome (NCS) comes into focus.”

“An even harder gut punch came just a few days before I was set to come home to Montana. As I am walking out of my post-operative appointment, I feel it: the same left flank pain that has plagued me for a decade. All of my relief, and much of my hope, have evaporated. Back to square one, I start to cry.”

# METHODS & RESULTS

The 25 question, anonymous survey collected responses from individuals aged 18 to 65+, with 6 aged 18-25, 9 aged 26-35, 7 aged 36-45, 3 aged 46-55, 1 aged 56-65, and 1 aged 65+. Gender distribution included 1 male, 25 females, and 1 preferring not to disclose. Participants came from various locations, including 17 from the United states representing 10 different states, and 4 other countries.

## **“Did you feel that your concerns were heard and understood?”**

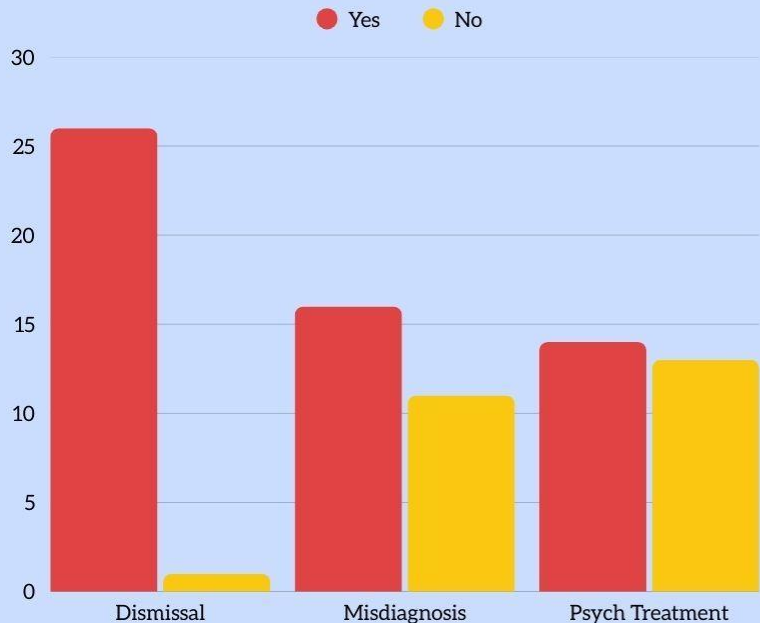
**RS #23, Female, Age 46-55**

"No! Because I am a female, slim, and fit looking who tried my hardest to continue with my life as normal, doctors didn't take my suffering seriously."

**RS #7, Female, Age 36-45**

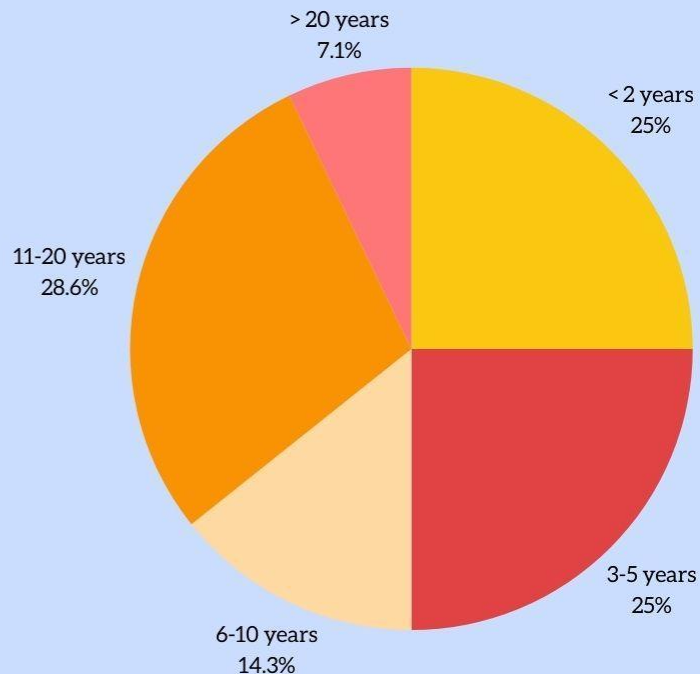
"No. I was dismissed by nearly everyone along the way including my primary care doctor."

# RESULTS



Did you ever feel **dismissed** by a healthcare provider, referred for **psychological treatment** instead of medical care, or given a **misdiagnosis**?

How long did it take from the onset of symptoms to receive an **accurate diagnosis**?



# CONCLUSION

## **If you could advise healthcare providers on how to improve their understanding and treatment of Nutcracker Syndrome, what would you say?**

“Research about it! We shouldn’t be the ones telling you what to do or trying to persuade to believe our pain is real.”

“Be nice, be kind, be curious, don’t make absolute statements about this you don’t know much about. Just be empathetic.”

“Listen to patients. Do not dismiss or write them off, their pain and suffering is real.”

“Have confidence in the patient's competence!”

“If you simply do not know how to help someone with NCS, say that. I’d rather a doctor look me in the face and say “yes you have this but I don’t know how to help. I will find someone who does”

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# THANK YOU

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