

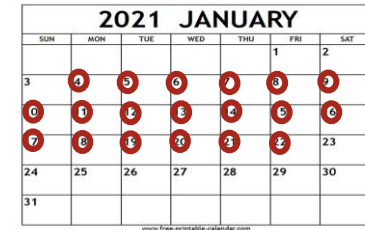
# Erythromelalgia Survey 2021

# Survey Process

- **Survey format: conducted 100% online . . . PC, tablet, smartphone . . .**



- **Dates the survey portal was available for participation:**  
**January 4, 2021 to January 22, 2021**



- **Survey reach:**
  - **Survey description and link to the survey questions were made available and seen as follows:**

Emails sent directly to all TEA registered members	3,300 emails sent	1,066 opened
Posts shared on TEA Facebook page	3,642 followers	reached 596 individuals
Posts shared on Fans of TEA Facebook page	247 followers	reached 37 individuals

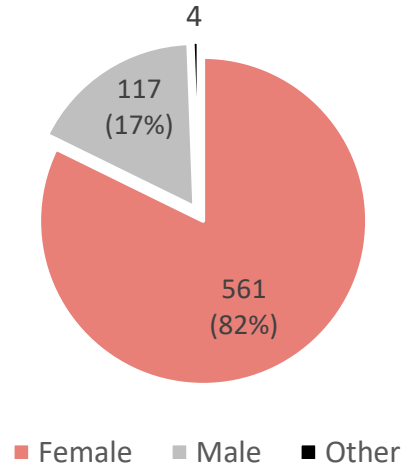
# Survey Process

## The numbers:

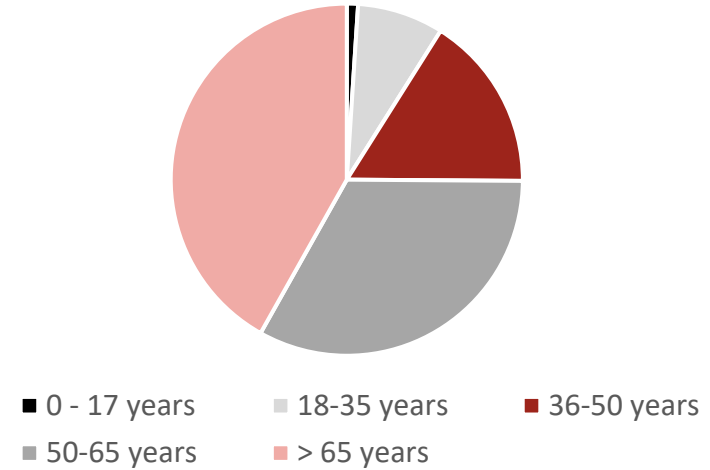
Total estimated # of people the survey was sent to:	7,189	
Total estimated # of people that opened the survey announcement:	1,699	23.6% of total survey announcements sent
Total # of people that completed and returned the survey:	683	40% of total survey announcements opened and read by recipients

# Respondent Demographics

## Gender:



## Age at time of survey:

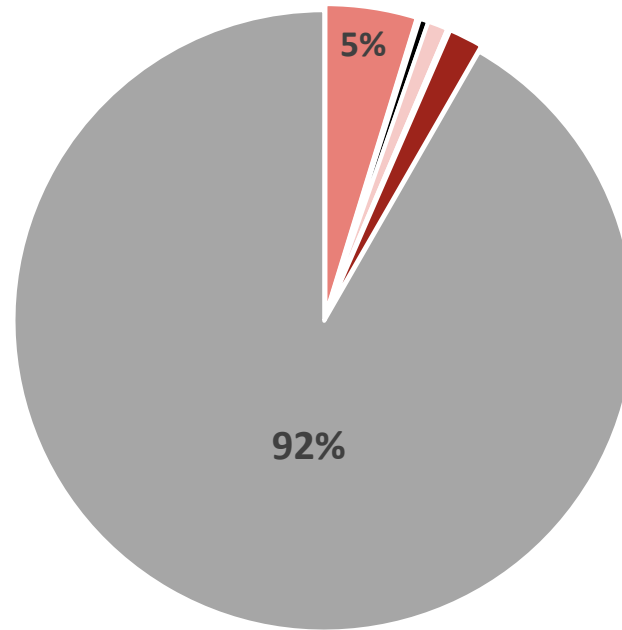


Age at time of survey:	Female	Male	Other	Grand Total
0 - 17 years	4	2	1	7
18-35 years	45	6	2	54
36-50 years	93	16	1	110
50-65 years	193	32	0	225
> 65 years	224	61	0	285

*Note: Females are more likely to respond to surveys which can skew the results*

# Respondent Demographics

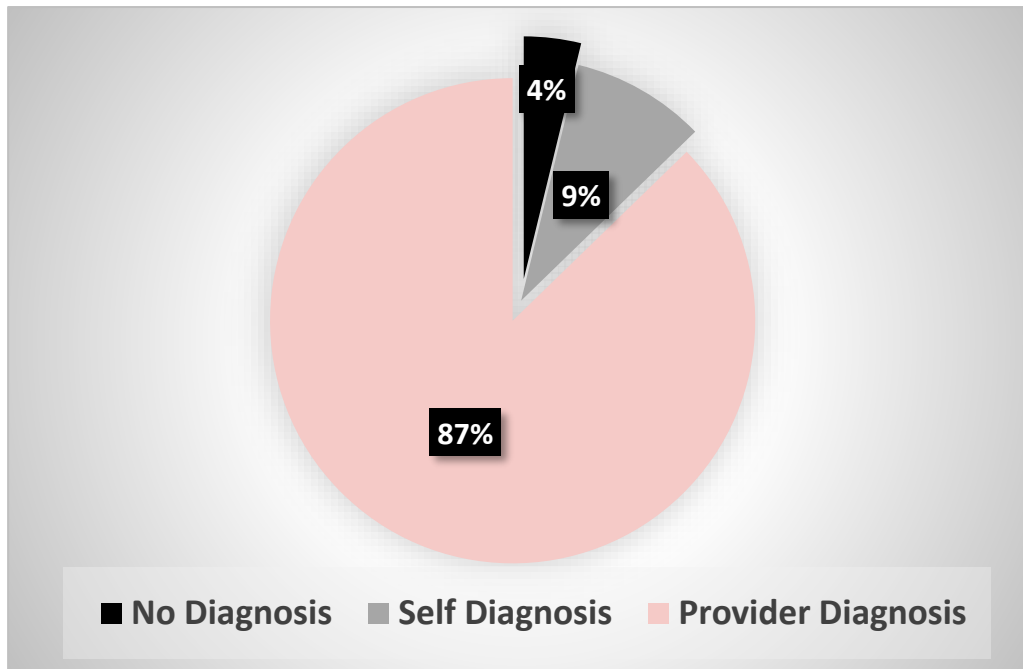
## Ethnicity:



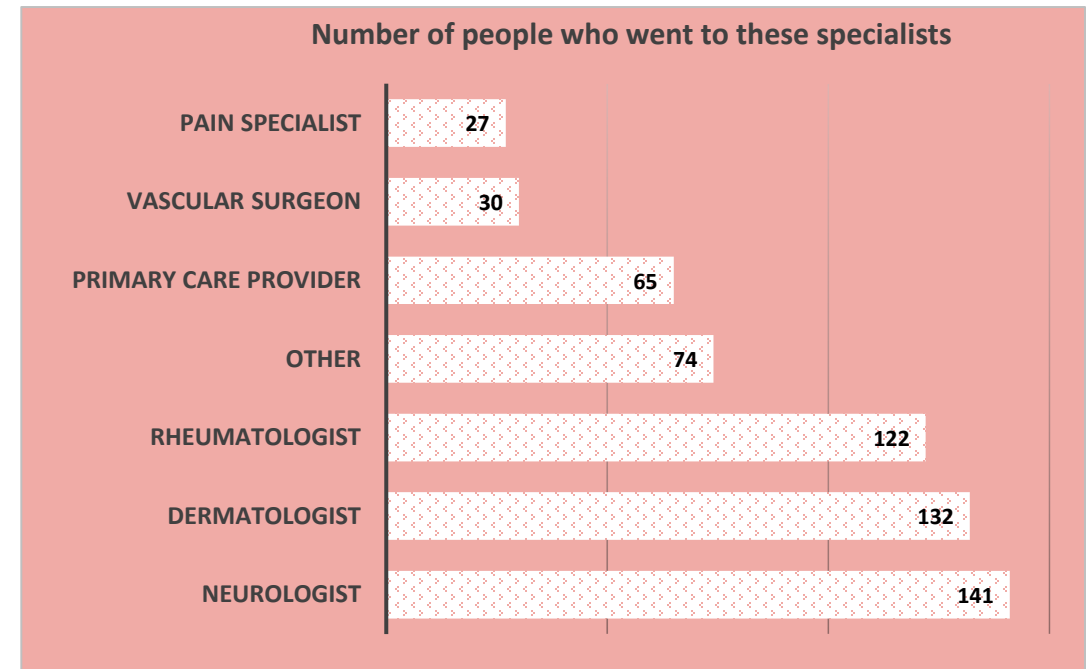
- Other
- Black or African American
- American Indian or Alaska Native
- White
- Native Hawaiian or Other Pacific Islander
- Asian
- Hispanic or Latinx

# Diagnosis Data

## Survey participants' diagnosis process:

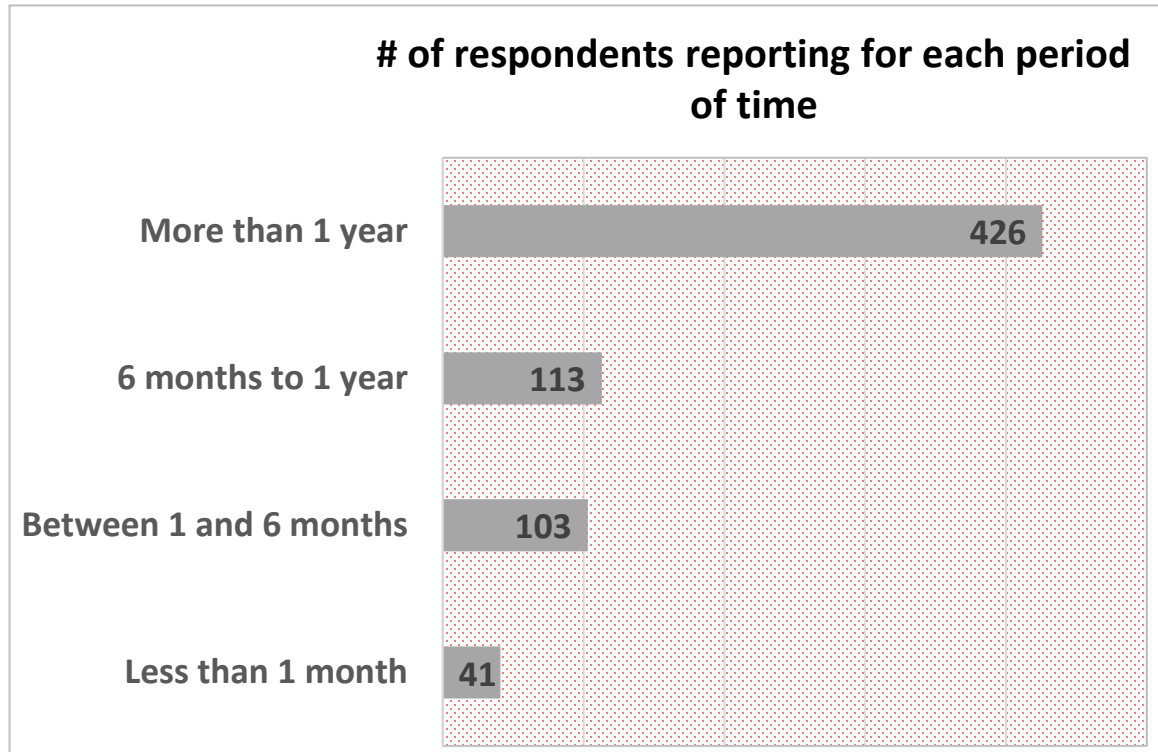


## Provider that made diagnosis:



# Diagnosis Data

## Length of time to get a diagnosis of EM:



Why the delay in diagnosis:	# of respondents
Provider unfamiliar with EM	479
Initially misdiagnosed	171
Mild symptoms	103
Live far from specialist	46
Insurance Barriers	18

# Diagnosis Data

Genetic testing to confirm EM diagnosis:

	# of participants
No	531
Unsure	122
Yes	30

For those that responded 'Yes' – this is the breakdown of the gene specified:

Nav1.7 (no other specifics)	4
Nav1.7 (with further specifics):	
SCN9A	3
L858H	1
SCN10A/SCN9A	1
SCN11A	1
JAK2 (Polycythemia Vera)	1
<b>Total Nav1.7</b>	<b>11</b>
<b>Don't know</b>	<b>14</b>
<b>No related genetic mutation found</b>	<b>5</b>
<b>Total</b>	<b>30</b>

Related question . . . 'Do you have any relatives that have been diagnosed with EM?'

No 521;  Not Sure 121;  Yes 41



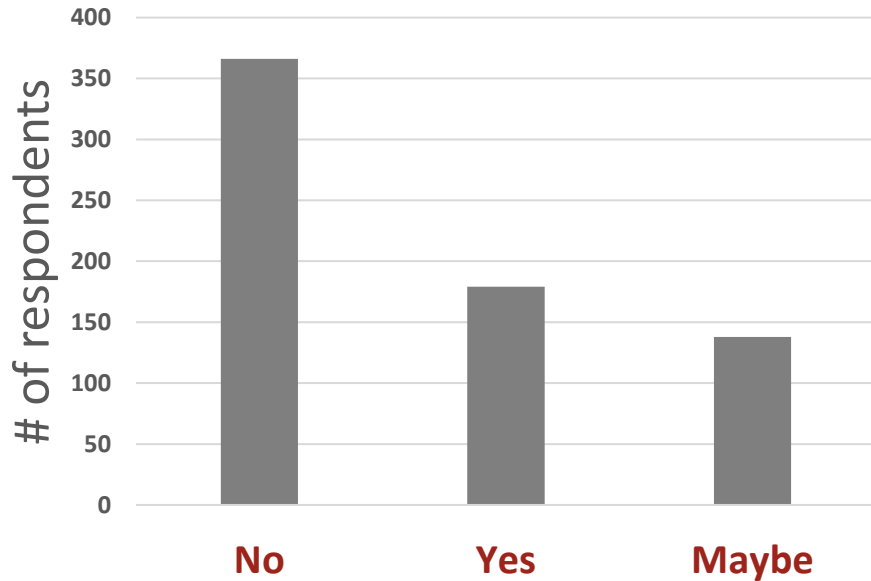
# Other Diagnoses

Most reported comorbidities of survey respondents:

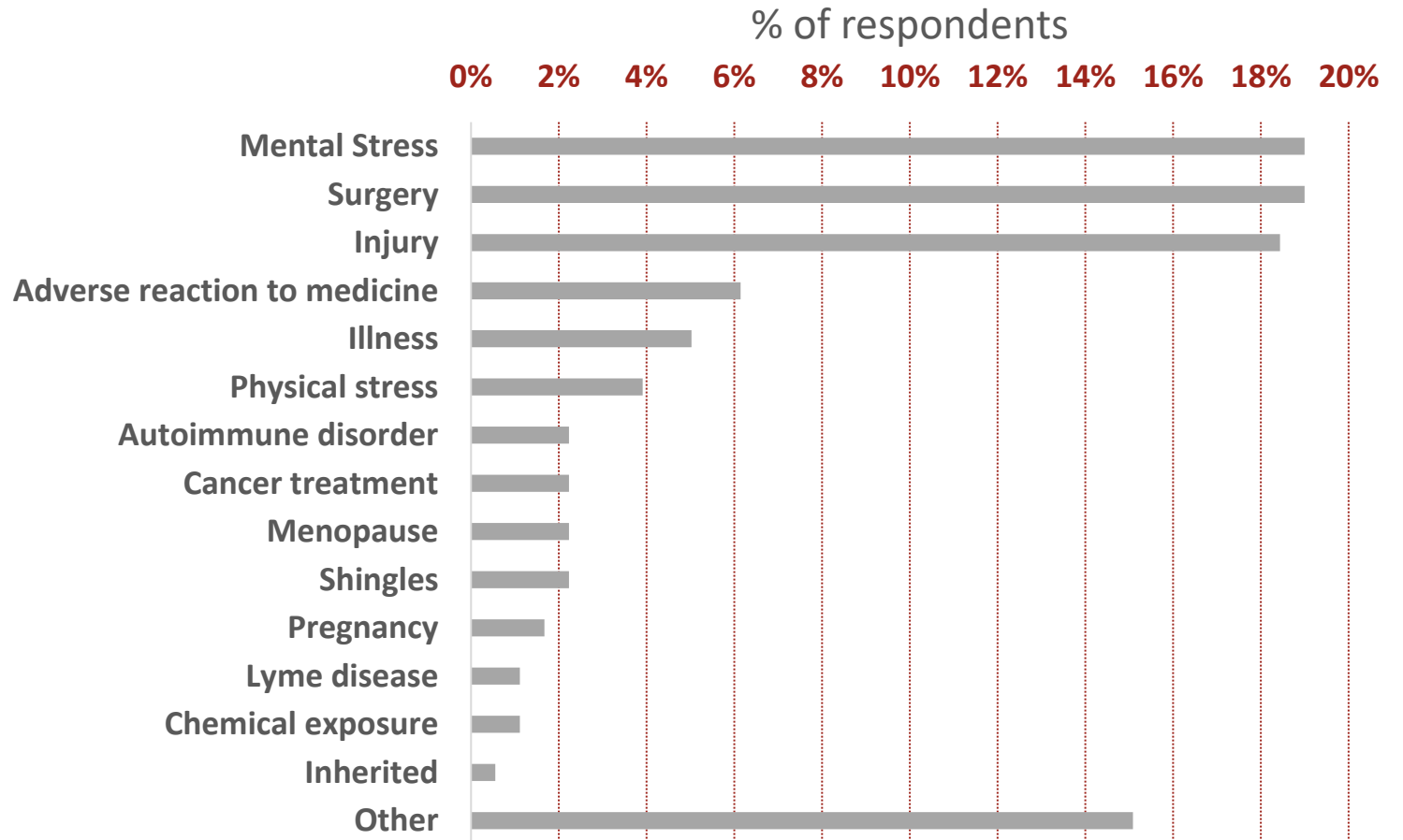
Disease or condition	# reported
Raynauds	42
Fibromyalgia	39
Small Fiber Neuropathy	24
Unspecified autoimmune disorders	20
Diabetes	16
Hashimoto's disease	16
Lupus	14
Migraines	14
Dysautonomia	9
Rosacea	8
Polycythemia Vera	6
Lyme	4
Multiple Sclerosis	4

# Symptom Data

Was there a specific event that triggered the first EM symptoms?



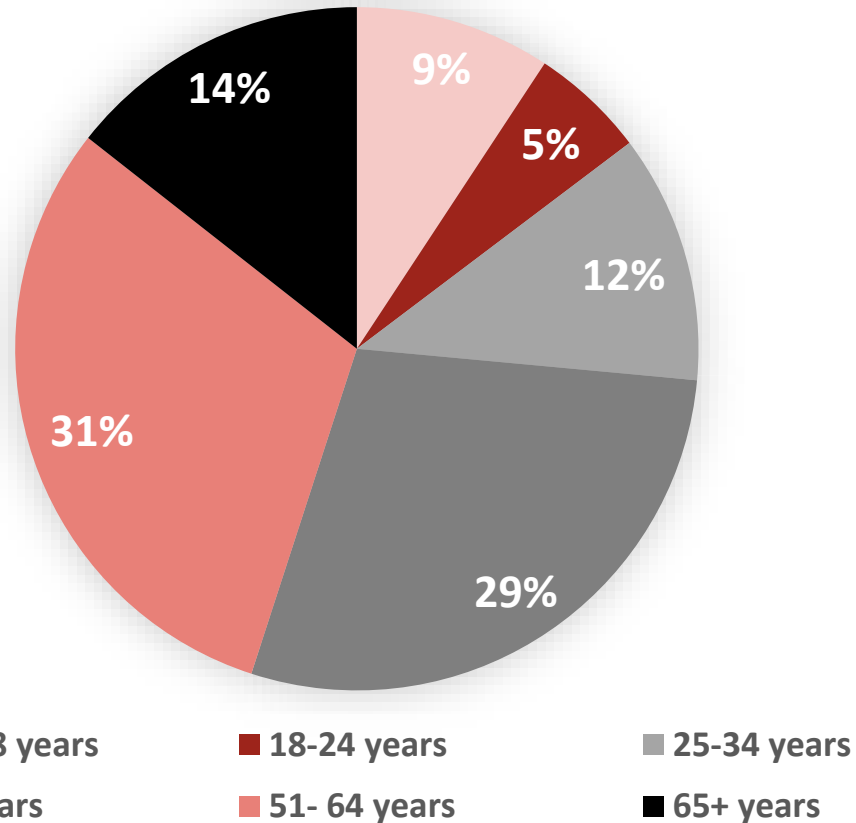
Triggering events or conditions reported:



# Symptom Data

## Age at symptom onset:

% of respondents for each age group:



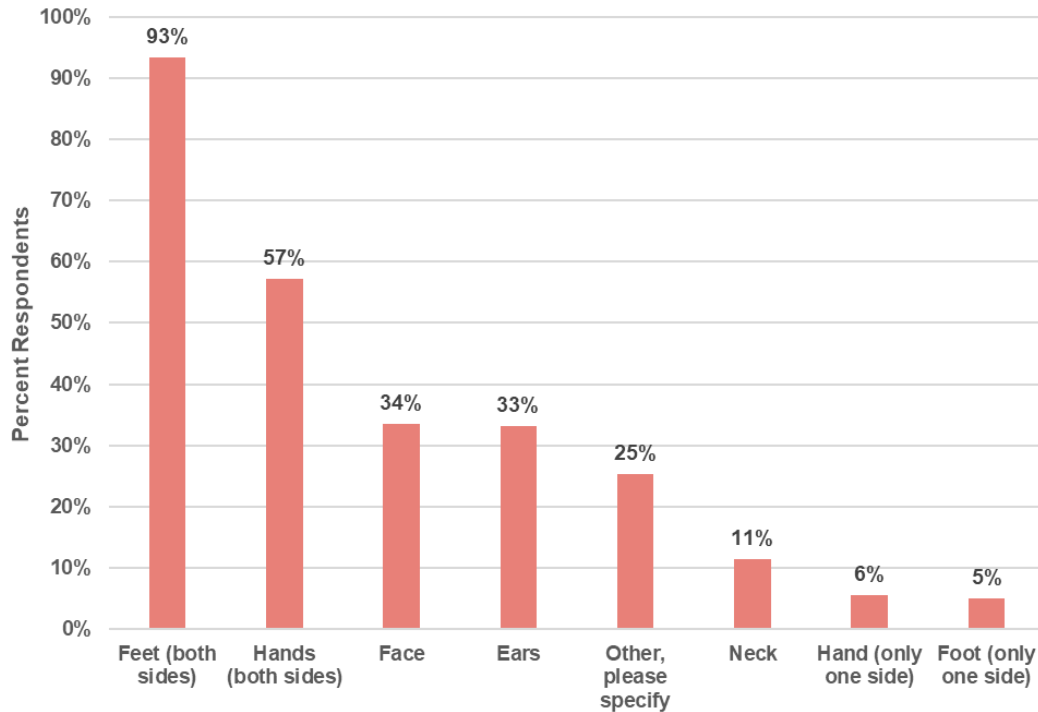
# of respondents for each age group:

Under 18 years	63
18-24 years	37
25-34 years	80
35-50 years	194
51-64 years	208
65+ years	98
Don't know	3
<b>Grand Total</b>	<b>683</b>

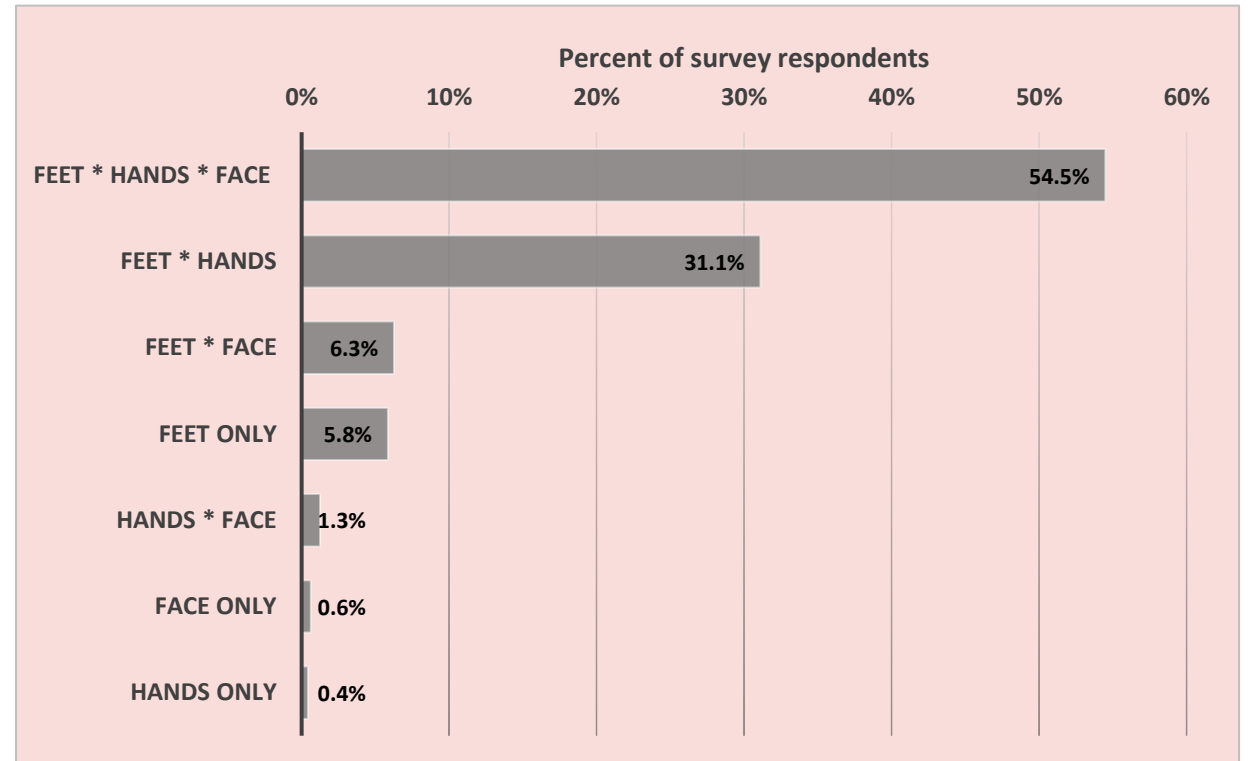
# Symptom Data

## Location(s) on the body of EM flares:

The following shows the number of participants who have flaring in **at least one** of the following areas:

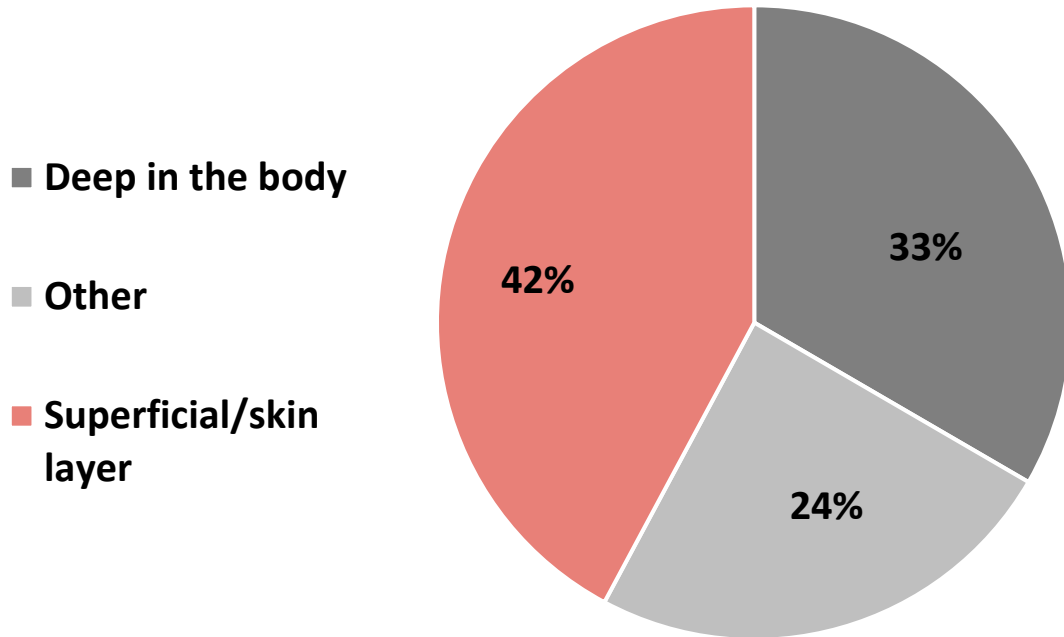


Flaring occurs in **multiple locations** in the majority of survey participants:



# Symptom Data

## Depth of pain during EM flaring:

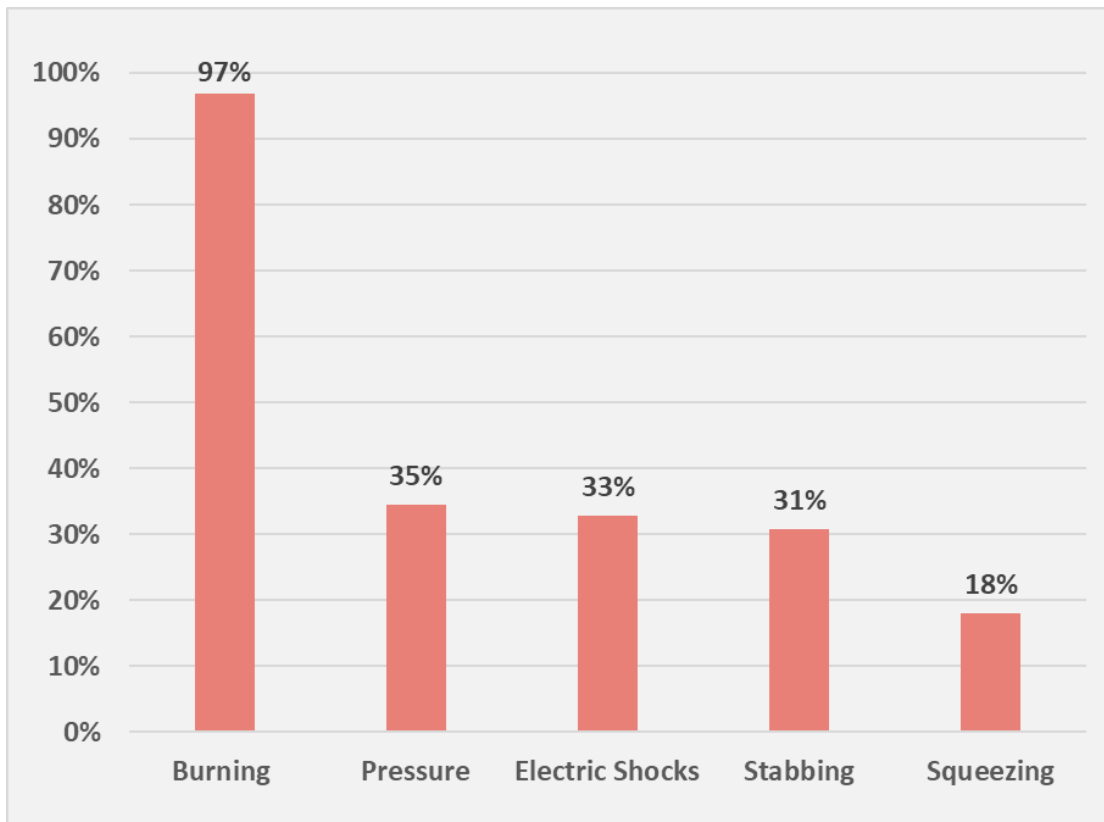


## Pain changes over time (since first becoming aware of symptoms):

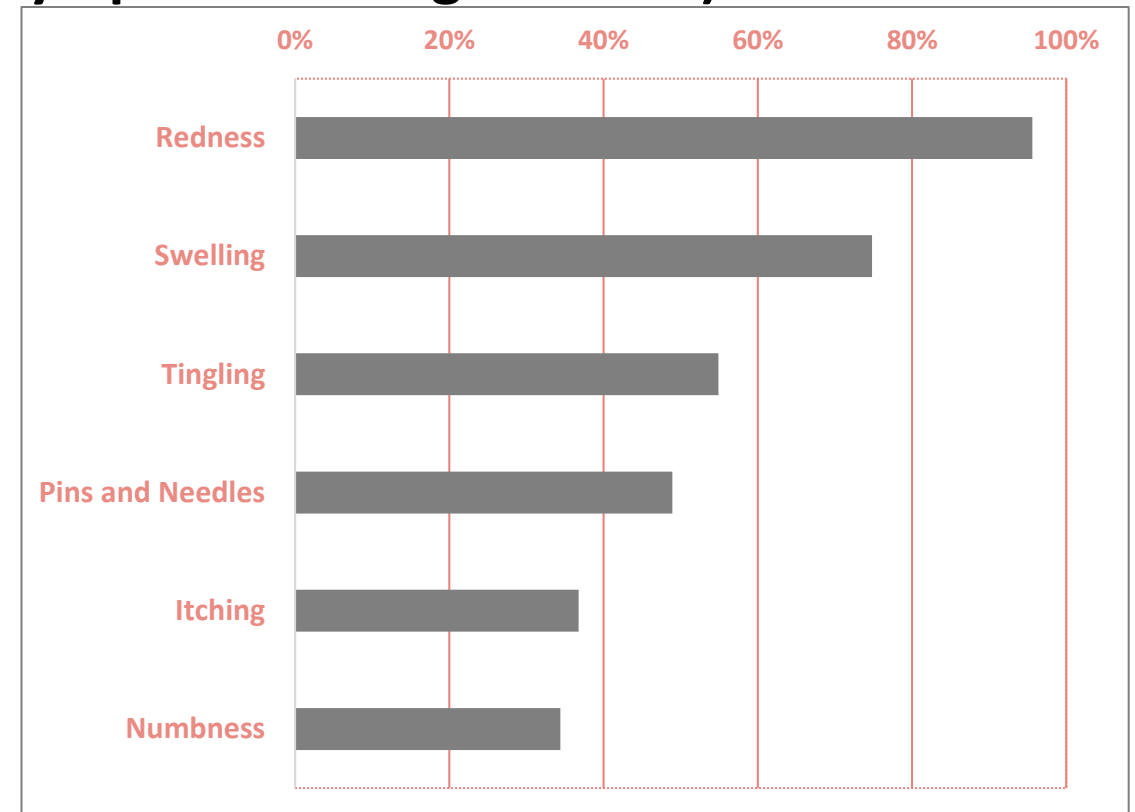
		# of respondents
<b>Fluctuated</b>	Now About the Same	102
	Now Better	114
	Now Worse	103
<b>Steady</b>	Stayed about the same	97
	Steadily better	40
	Steadily worse	214
<b>Not sure</b>		<b>13</b>

# Symptom Data

Percentage reporting each of these pain descriptions:



Additional pain descriptions (percentage reporting having one or more of these symptoms during EM flare) :

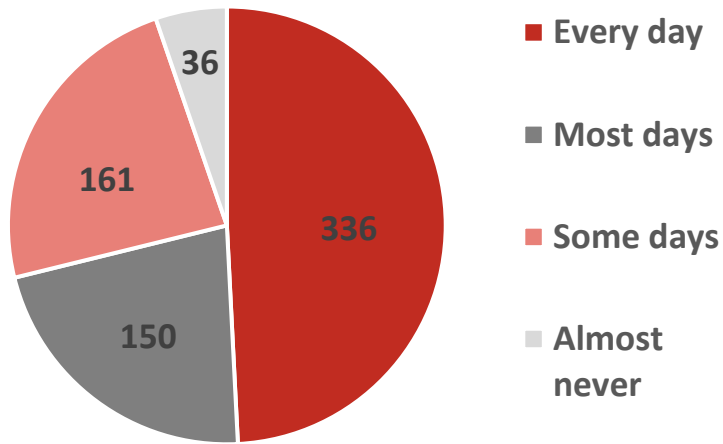


Many people reported multiple characteristics of pain

# Symptom Data

## Frequency of EM flare-ups

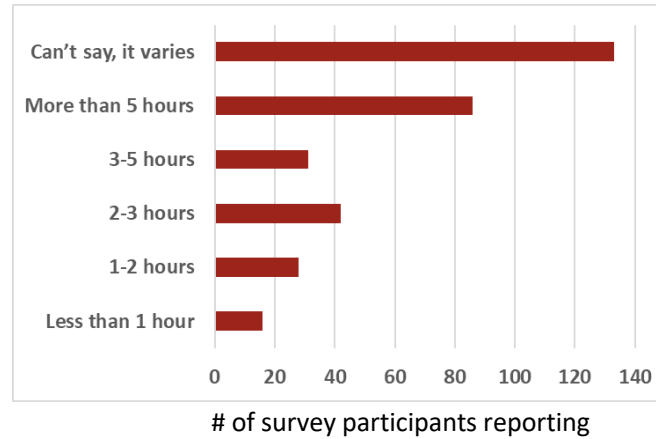
(also known as 'flaring'):



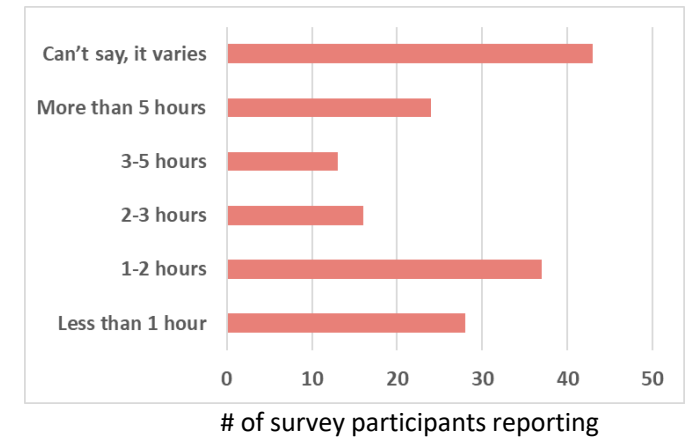
# of respondents for each level of frequency

## How long do the flares last?

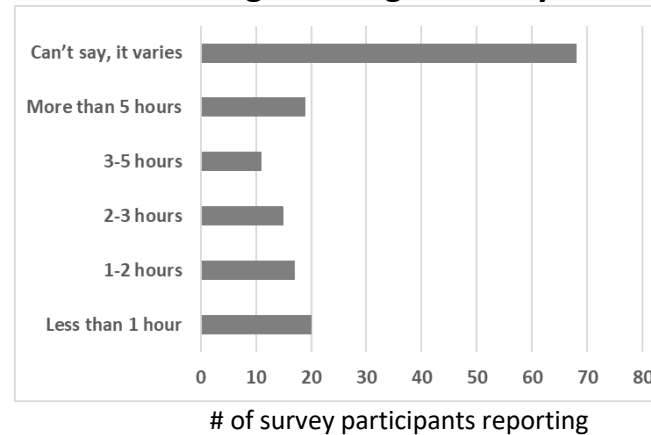
For those who get flaring every day:



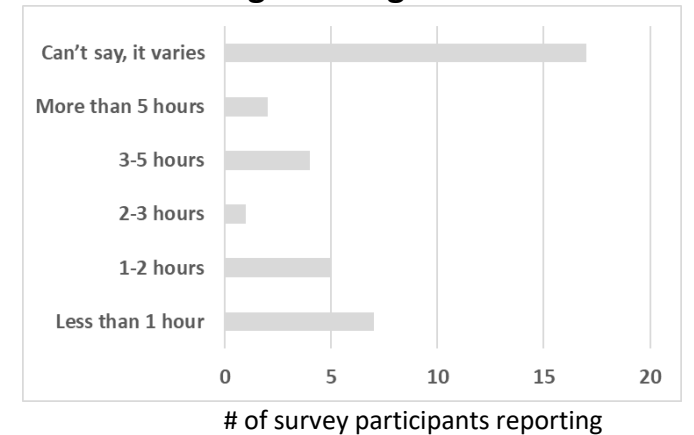
For those who get flaring some days:



For those who get flaring most days:

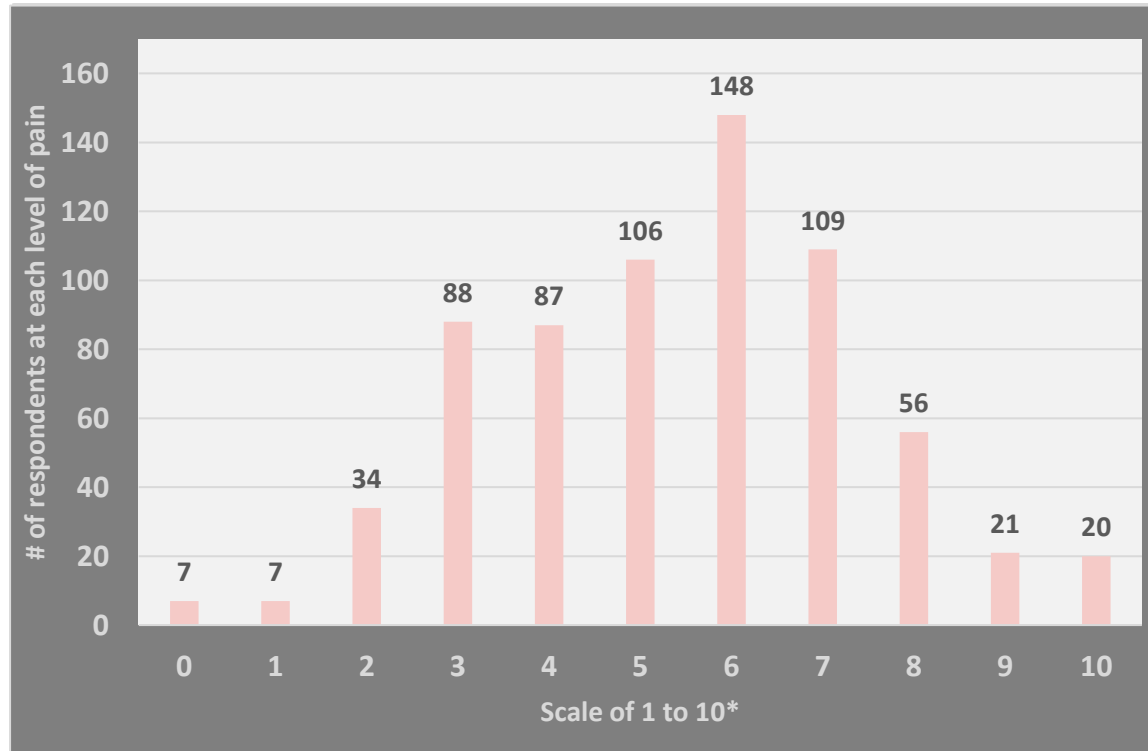


For those who get flaring almost never:

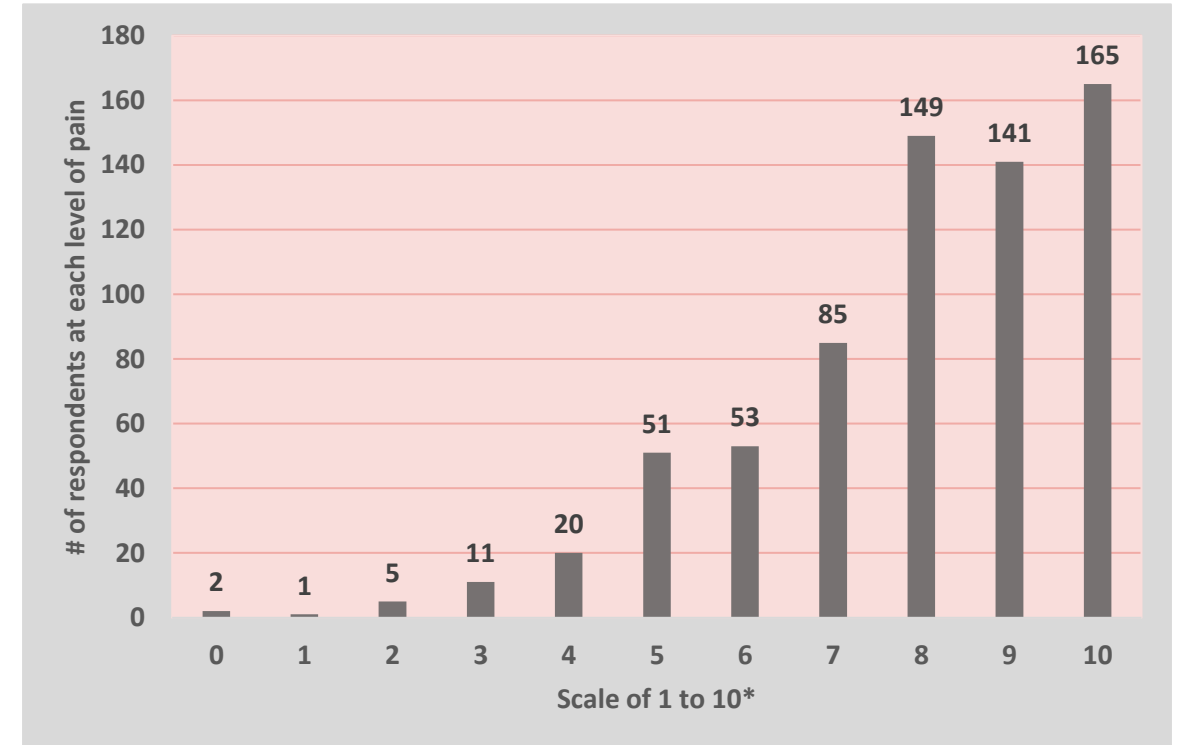


# Symptom Data

## Typical daily EM Pain:



## Worst case EM Pain:



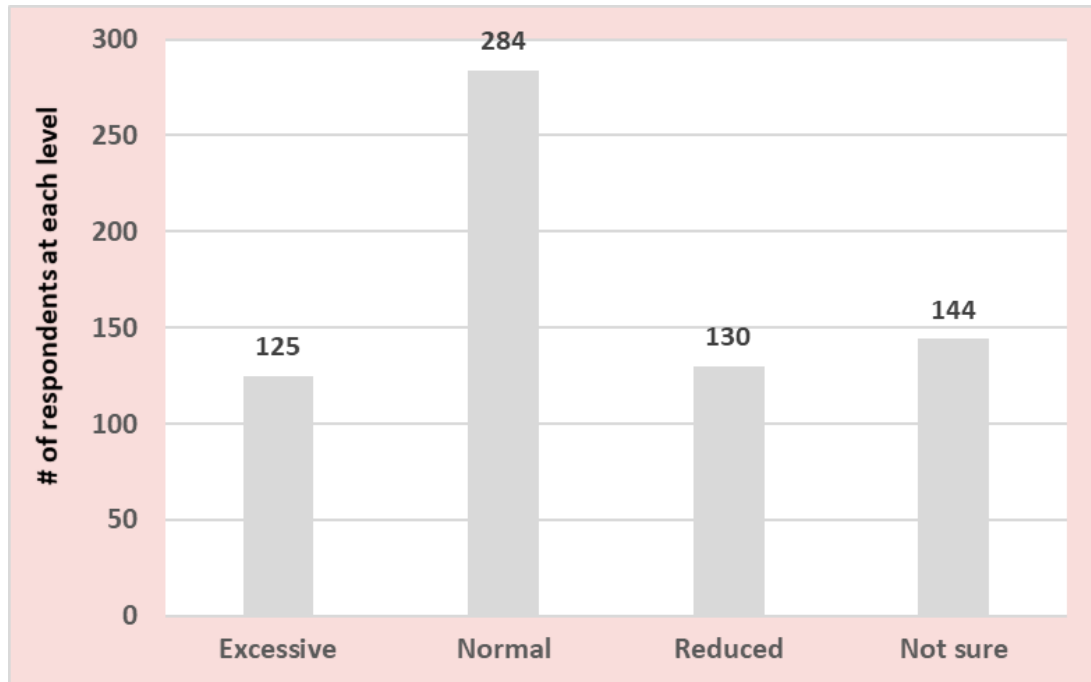
\*0 = no pain and 10 = most severe pain



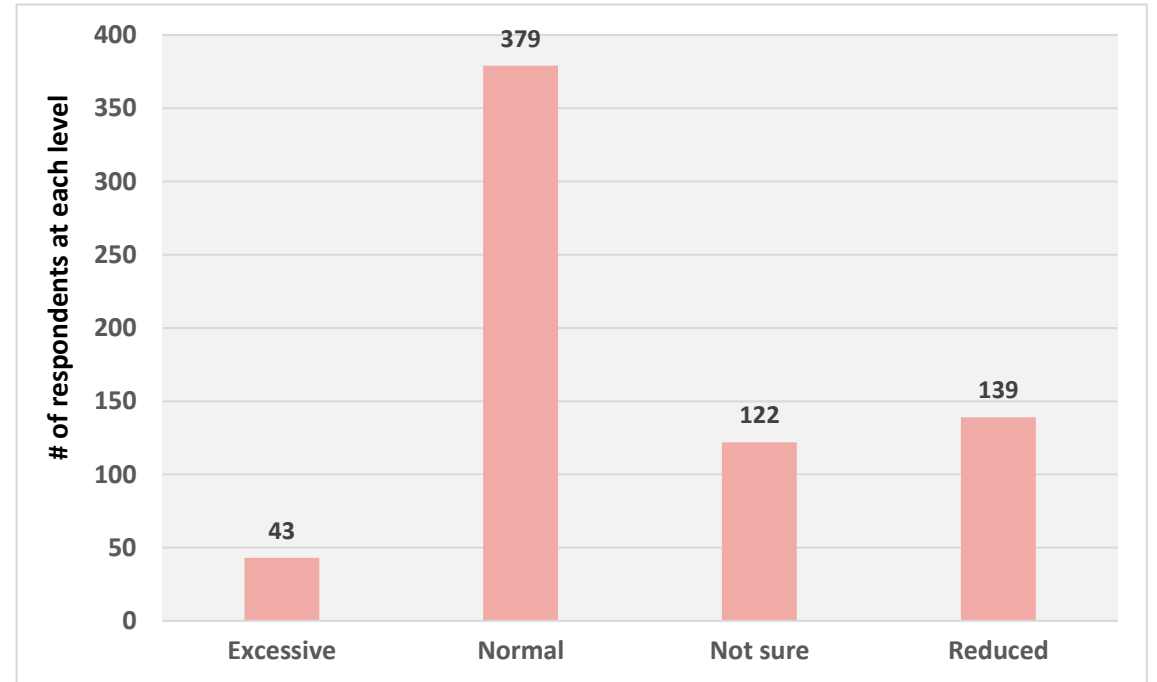
# Symptom Data

Survey respondents reported their level of sweating:

**During EM flares:**

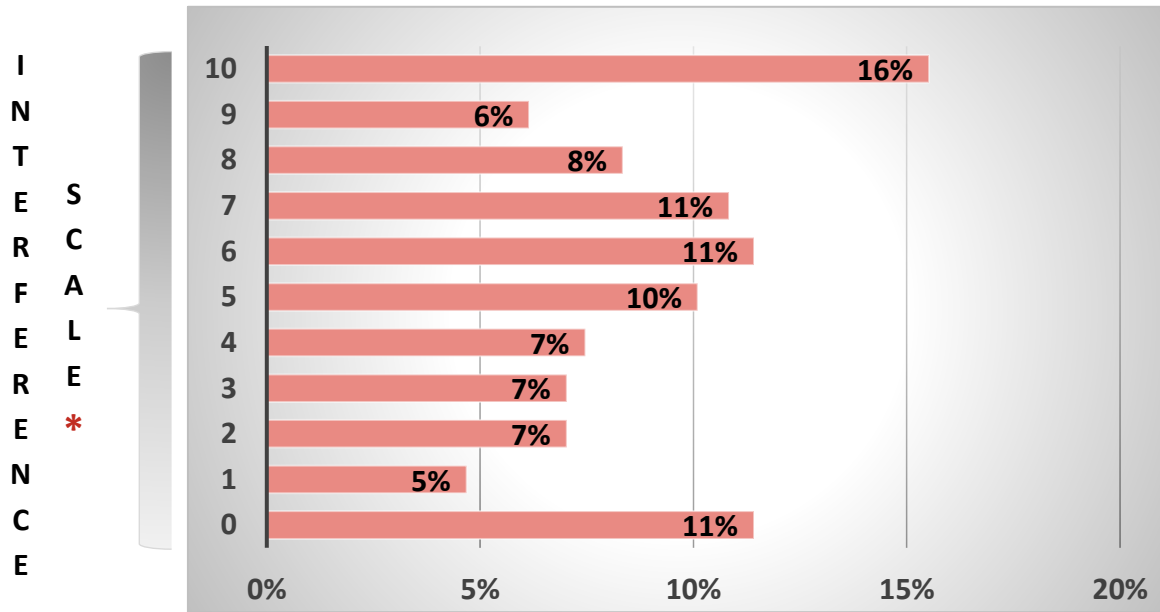


**Not in a flare:**

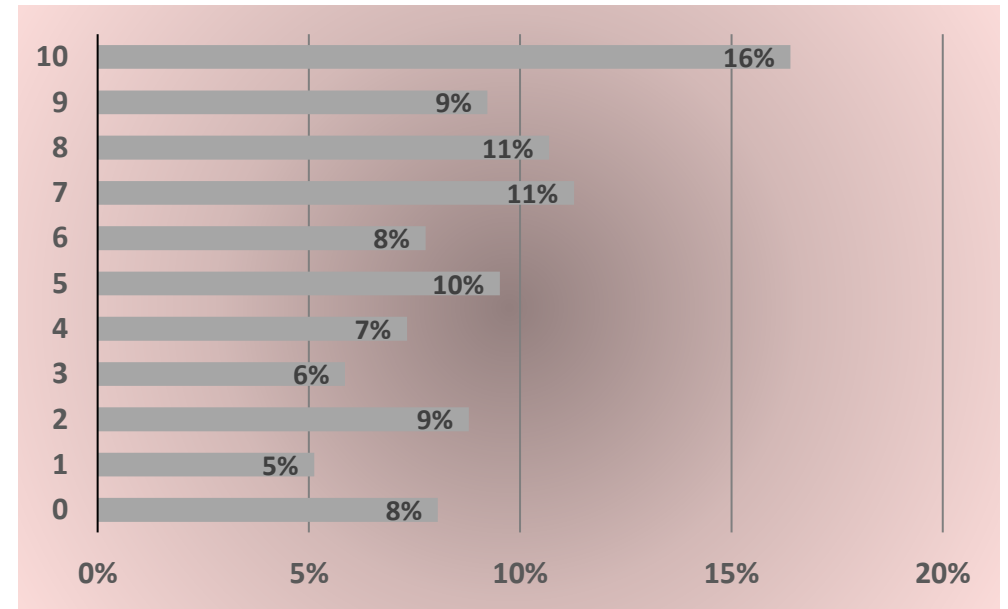


# Quality of Life Data

How much does the pain of EM interfere with your daily life?



Very similar results for the question: How much does EM pain interfere with your enjoyment of life?

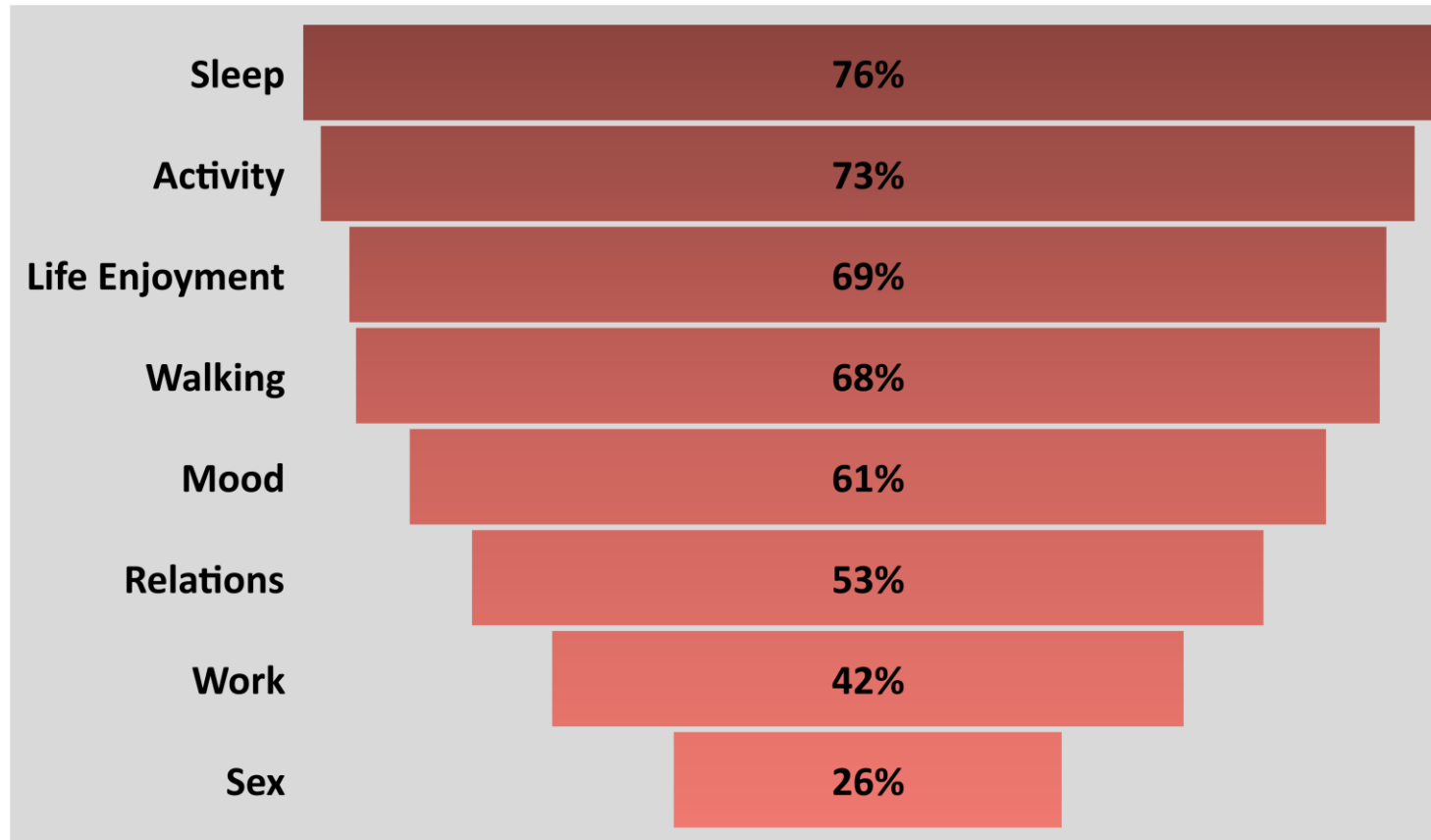


PERCENT REPORTING AT EACH LEVEL OF INTERFERENCE

\* Scale: 0 = no interference with daily life and 10 = completely interferes with daily life

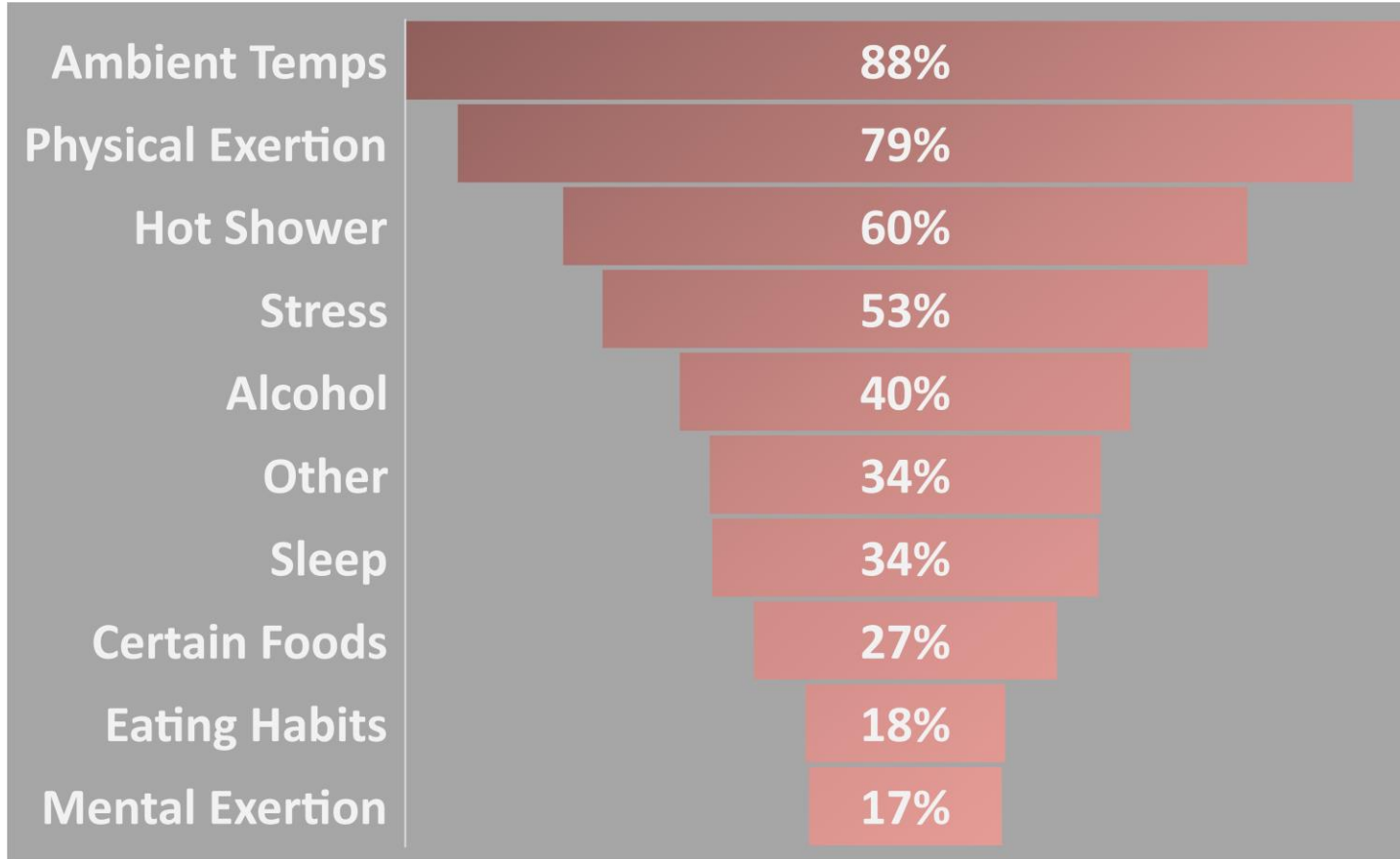
# Quality of Life Data

**Percent of survey participants reporting these aspects of life have been negatively affected by EM symptoms:**



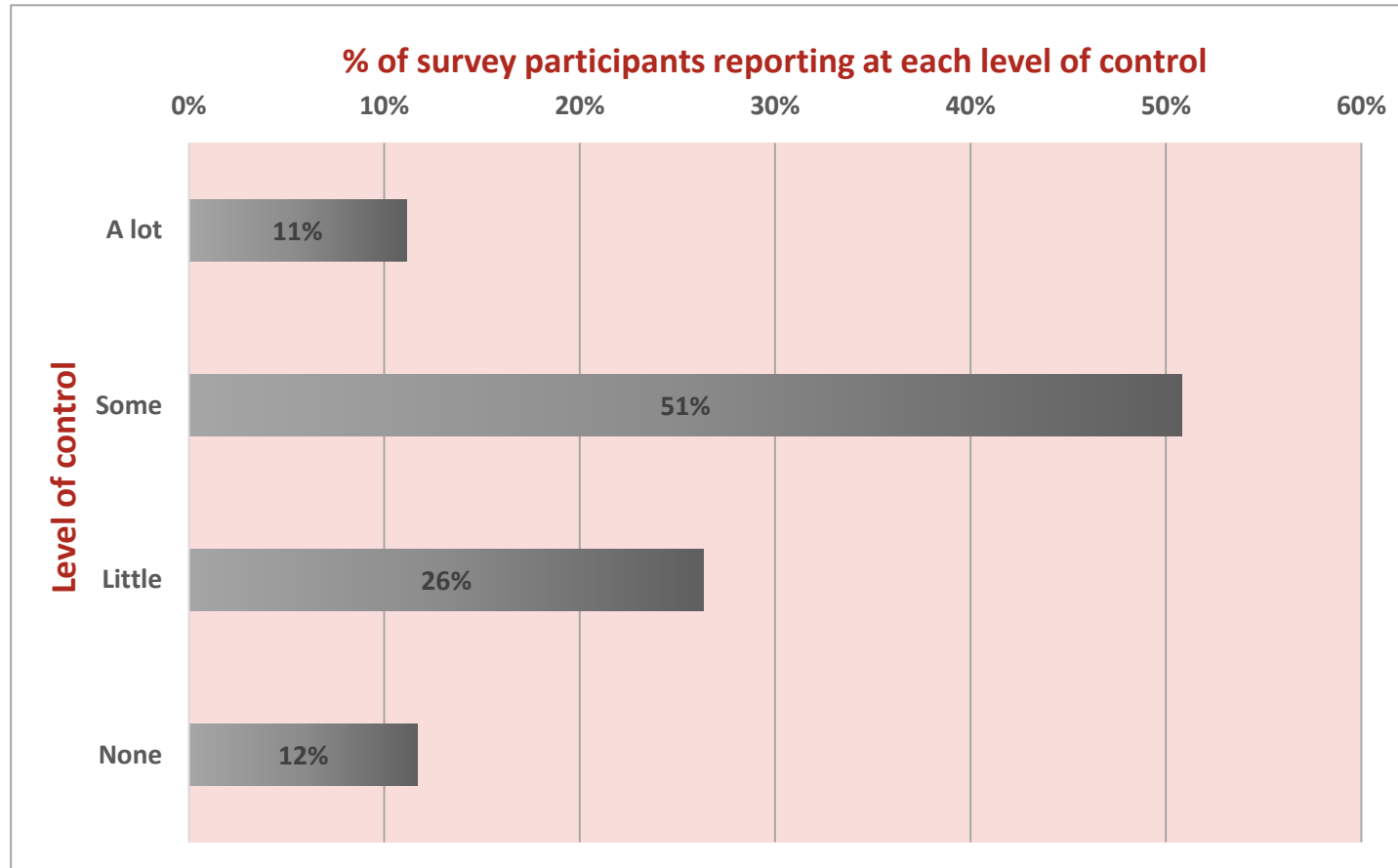
# Quality of Life Data

**Percent of survey participants reporting these factors trigger their EM symptoms:**



# Quality of Life Data

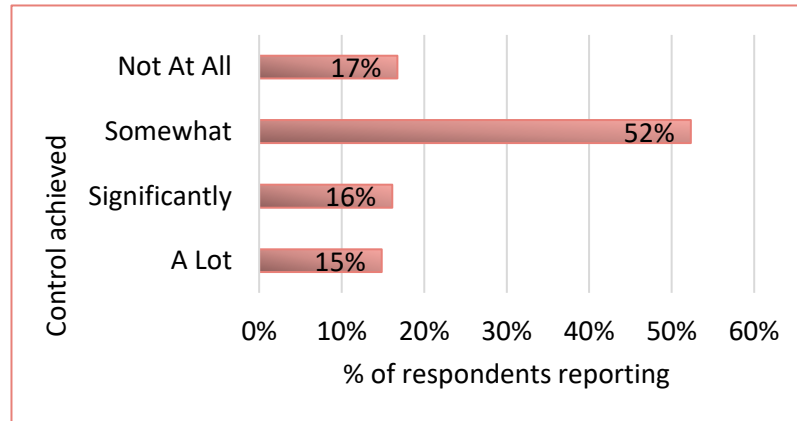
## Overall level of control reported over EM flares/attacks:



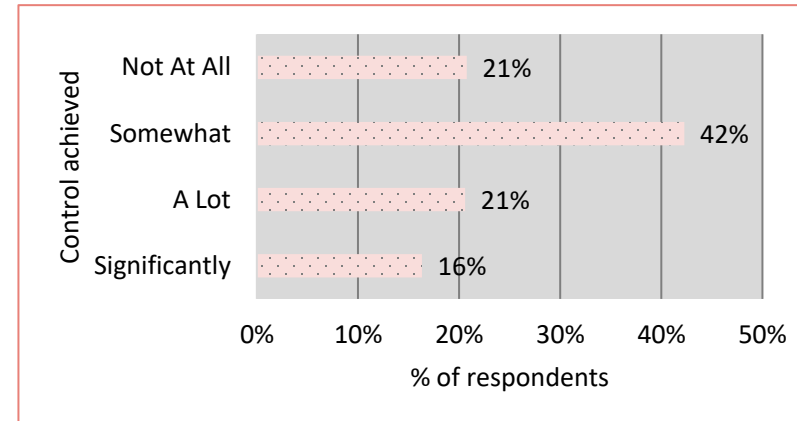
# Quality of Life Data

Survey takers were asked what level of control do they have over EM flares through:

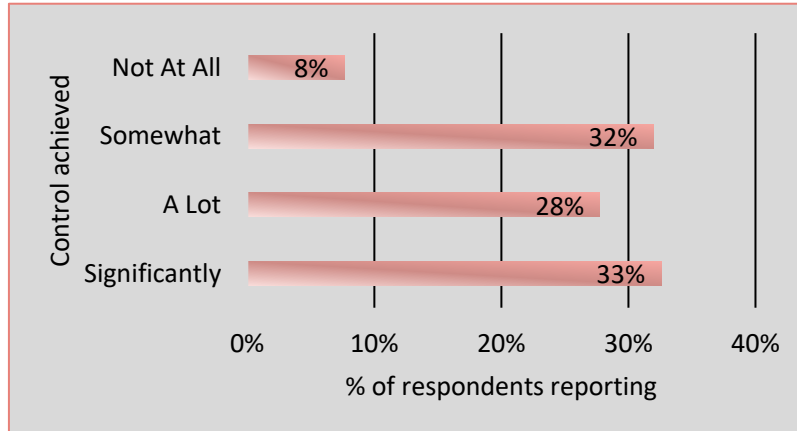
➤ **Lifestyle changes:**



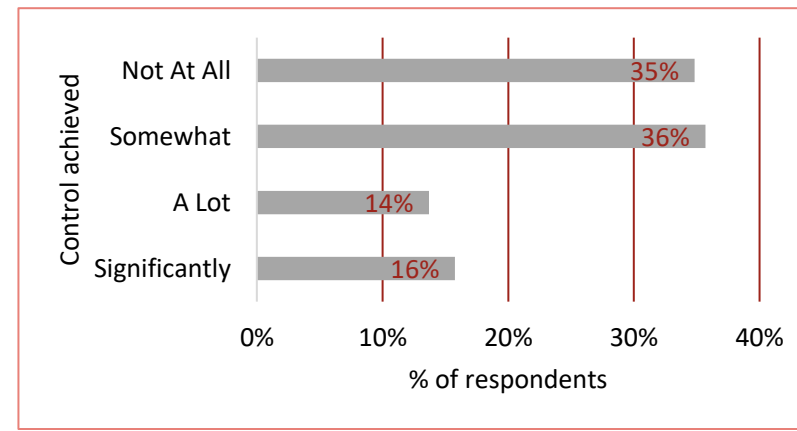
➤ **Resting and elevating effected areas:**



➤ **Cooling:**



➤ **Resting and elevating effected areas:**



# Treatment data

## Medications most reported as tried or currently using (and the affect on symptoms):

MEDICATION NAME	Medication Class	Total # who tried this drug	Of those who reported using the medication, below details the level of improvement of symptoms (if any) from the drug				
			A Lot	Some	Little	None	Worsened
Aspirin	NSAID	67	6	9	3	49	
Gabapentin (Neurontin)	Anticonvulsant and nerve pain medication	34	3	7		24	
Pregabalin (Lyrica)	Nerve pain	19	1	2	1	14	1
Duloxetine (Cymbalta)	Antidepressant and nerve pain medication	13		1	1	8	3
Venlafaxine (Effexor)*	Antidepressant and nerve pain medication	8	1	3	1	2	1
Amytriptyline (Elavil, Endep)	Tricyclic antidepressant	7		1	1	5	
Mexiletine	Antiarrhythmic	5	1			4	
Amlodipine (Norvasc)	Calcium Channel Blocker	6		3		1	2
Nifedipine	Calcium Channel Blocker	4		1		2	1

\*also known as a serotonin-norepinephrine reuptake inhibitor (SNRI)

Take-away: The medication most attempted is aspirin with 73% reporting no improvement and 22% reporting at least some improvement. **The overall majority of the respondents (75%) had little to no improvement (or worsening) of EM symptoms from the medications attempted.**

# Treatment data

Other medications reported as tried or currently using (and the affect on symptoms):

Medication Name	Medication Class	A Lot	Some	Little	None	Worsened	Total # Respondents that tried the medication
Midrodine	Alpha-adrenergic agonists				1		1
Carbamazepine	Anticonvulsant and nerve pain medication					2	2
Clonazepam (Klonopin)	Anticonvulsant and anxiety				2		2
Carbamazepine (Tegretol)	Anticonvulsant and nerve pain medication				1		1
Topiramate (Topamax)**	Anticonvulsant and nerve pain medication					1	1
Clopidogrel	Antiplatelet drug				1		1
Bisoprolol	Beta blocker				1		1
Labetalol	Beta blocker		1				1
Propranolol	Beta blocker				2	1	3
Adalat XL	Calcium Channel Blocker					2	2
Diltiazem (Cardizem)	Calcium Channel Blocker	1					1
Clonidine	Sedative and Antihypertensive				1		1
Isotretinoin (Accutane)	cystic acne			1			1
Maxide	Diuretic		1				1
Pentoxifilline	Hemorrhologic agents*				1		1
Progesterone (Prometrium)	Hormone			1			1
Morphine	Narcotic					1	1
Oxycodone	Narcotic		1				1
Tramadol	Narcotic	1			1		2
Ibuprofrn	NSAID		2				2
Indomethicin	NSAID		1				1
Hydrocodone (Vicodin)	Opiod	1	1				2
Other Opioids	Opiod			2	1		3
Antihistamines	OTC antihistamines		3		3		6
Cetirizine (Zyrtec)	OTC antihistamines				1		1
Acetaminophen	OTC pain reliever				1		1
Desloratidine	Prescription antihistamine			1			1
Rupatadine	Prescription antihistamine				1		1
Fluoxetine (Prozac)	SSRI		1		1		2
Escitalopram (Lexapro)	SSRI				2		2
Prednisone	Steroid	1			2		3
Desipramine	Tricyclic antidepressant		1				1

Take-away: A wide array of medicines have been tried by the EM population with very limited success in reducing the pain and discomfort of the symptoms.



# Alternative treatments data

A sample of other alternative treatments reported:\*

	Improved symptoms	No effect on symptoms
Acupuncture	17	108
Biofeedback	3	1
CBD	7	13
Compression stockings	5	0
Lidocaine	5	3
Marijuana	3	5
Meditation	5	4
Nerve block	1	7
THC	4	2

\*There were numerous other items listed that one or two participants reported having tried that are not listed in this document such as homeopathic tinctures, Epsom salts, Botox and TENS unit.