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Use of low dose naltrexone and hydroxycarbamide for mast cell disorders (ISM, MCAS, HaT)

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Introduction

Mast cells (MC), in addition to being present in bone marrow, are ubiquitous lining the gut, lungs, uterus, bladder as well as the brain. MC can release >1000 mediators, causing multiple symptomologies resulting in difficulties in symptom control in mast cell disorders.

There are several mast cell disorders that cause mast cell symptoms resulting in difficulties in symptom control in mast cell disorders. There are several mast cell disorders that cause mast cell symptoms including Systemic Mastocytosis (ISM), Mast Cell Activation Syndrome (MCAS) and Hereditary alpha tryptasemia (HαT) Hydroxycarbamide together with low dose naltrexone (LDN) have been shown to be helpful together with antihistamines in mast cell patients, in calming their symptoms. Hydroxycarbamide is an old and well known drug in treatment of myeloproliferative conditions and also in Sickle Cell conditions, with cell load reduction and pain reduction in HbSS.

LDN is used as an extremely low dose compared to standard dose Naltrexone, and we prescribed it as 4.5mg od.

Method

Patients were identified from the local data base and review of all symptoms were recorded by patients (Table 1). All the patients in this study were female.

Date:_____/_____/_____

MAST CELL ACTIVATION SYNDROME SYMPTOM INDEX

NAME: NHS no.

Frequency: 0=never, 1 = once/mo., 2 = few times/mo., 3 = few times/wk., 4 = few times/day, 5 = constantly
Severity: 0 = never, 1 = mild, 2 = mild to moderate, 3 = moderate to severe, 4 = severe

	Frequency	Severity
GENERAL - Constitutional		
Chills		
Fever		
Fatigue		
Weight loss		
Skin		
Flushing		
Flushing with sweating		
Itchy skin		
Hives (red, itchy bumps)		
Swelling of lips, eyes or face		
Respiratory		
Itchy eyes or nose		
Runny nose		
Blocked nose		
Problems taking a deep breath (throat swelling)		
Feeling short of breath		
Hoarseness		
Wheezing		
Cardiovascular		
Palpitations with rapid heart beats		
Fainting or near fainting episodes		

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Table 1Continued……

Date:_____/_____/_____

MAST CELL ACTIVATION SYNDROME SYMPTOM INDEX

NAME: NHS no.

Frequency: 0=never, 1 = once/mo., 2 = few times/mo., 3 = few times/wk., 4 = few times/day, 5 = constantly

Severity: 0 = never, 1 = mild, 2 = mild to moderate, 3 = moderate to severe, 4 = severe

	Frequency	**Severity**
Chest pain		
Gastrointestinal		
Diarrhoea		
Abdominal pain		
Abdominal cramping		
Bloating		
Constipation and / or diarrhoea		
Heartburn		
Nausea		
Neurology		
Headaches		
Tingling or numbness		
Trouble with memory /thinking		
Sleep problems		
Dizziness (head spinning)		
Anxiety or panic attacks / depression		
Musculo-skeletal		
Muscle pain and / or tenderness		
Joint pain		
Obstetric/Gynae		
Heavy periods? Endometriosis? PCOS ?		
Pregnancy issues		
? EDS Y/N		
? PoTs Y/N		

Medications were commenced individually and gradually escalated, and patients completed document 1 again in clinic after treatment for three months.

The main aims of this project were to examine the use of LDN and Hydroxycarbamide in patients with mast cell disorders and also to assess clinical responses in patients with multiple symptoms.[1]

Results

Forty MCAS patients received LDN alone and showed improvement in joint pains, fatigue, gut and skin symptoms, whereas 20 MCAS patients did not tolerate LDN.[2]

Two female patients with c-kit positive ISM had bone pain which responded to LDN as well as their gut symptoms improving in both cases. A further patient with MCAS received a combination of Hydroxycarbamide and LDN, again with significant improvement in bone pain, fatigue, gut and skin symptoms.[3]

All the patients received mast cell stabilisers and antihistamines in addition prior to starting LDN +/- hydroxyurea, and all on this last medication had regular FBC blood tests.

Conclusion

Mast cell reactions are often difficult to manage, but the majority of our cohort benefitted from one or both of these drugs. LDN is an unfamiliar drug in most hospitals in the UK, but due to its positive effects in the majority of our patients, we have stocked it in our hospital pharmacy.

We recommend consideration of this drug combination and LDN can be sourced from Dickson's Chemist in Glasgow, which has considerable experience of LDN over many years.

Acknowledgement

None.

Conflict of interest

None declared.

References

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