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Analyzing Pain Medication Use and Adherence in Patients with Myotonic Dystrophy and Facioscapulohumeral Dystrophy

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Abstract
Objectives: Myotonic dystrophy (DM) and facioscapulohumeral dystrophy (FSHD) are two of the most common muscular dystrophies in adults. It has been reported that patients with these two disorders may suffer from pain and inadequate pain management. The purpose of this study is to analyze the current use of pain medications and develop a survey to assess pain medication use and adherence in this patient population.

Methods: Patients registered in the National Registry for DM and FSHD at the University of Rochester were surveyed on pain medication use and the most significant problem of their disease. After analysis of these surveys, an additional survey was created that contained questions specifically on pain medication use, adherence, and general questions about the patients' pain. Questions for the survey were devised from previous studies on medication adherence, questionnaires on medication adherence and beliefs, and questions from the Brief Pain Inventory.

Results: In the first survey, pain medication was used by 34% of the survey respondents (n=519/1527). Specifically, NSAIDs were used by 23.5% and opioids were used by 4% of survey respondents. In a separate survey, pain was reported as the most burdensome problem by 8% of patients (n= 27/355). This was greater than problems related with balance (n=10/355), fatigue (n=20/355), or gastrointestinal distress (n=8/355).

Conclusion: Despite the low reported response that pain was the most significant problem associated with their disease, the prevalence of pain medication use indicates that further study into the impact of pain and pain medication use in this patient population is warranted. Specifically, investigating questions about adherence, use, and beliefs toward pain medication will lead to an increased understanding of pain and its treatment in this patient population. This knowledge can lead to the ability of pharmacists to optimize pain management and to reduce adverse reactions to pain medications.

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Analyzing pain medication use and adherence in patients with myotonic dystrophy and facioscapulohumeral dystrophy

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Introduction

Myotonic dystrophy (DM) and facioscapulohumeral dystrophy (FSHD) are the two most common adult muscular dystrophies.[1,2] A National Registry was created at the University of Rochester Medical Center to connect muscular dystrophy patients and family members with research opportunities.[3]

Pain is a symptom that many patients in this population have experienced – 64% of DM patients and 82% of FSHD patients are said to experience pain.[4] Levels and locations of pain vary, although back pain is most common.[4,5] Pain can be a problematic and debilitating symptom for patients, so it is important to understand the impact of pain on DM and FSHD patients and how it's managed.

Methods

Patients registered in the National Registry for DM and FSHD at the University of Rochester are surveyed on medication use upon enrollment into the Registry (n=1527). In a separate survey (n=371), patients were asked about the most significant problem of their disease. Data was collected anonymously over the course of several months.

After analysis of these surveys, an additional 73-question survey was created containing questions on basic disease and pain information, pain medication adherence factors, beliefs on pain medication, specific questions on opioids and NSAIDs, and pain medication counseling. The survey was approved by SJFC IRB and the registry's Scientific Advisory Board and it will be electronically sent to eligible participants in the registry in May 2015.

Results

Of the 371 total responses, pain ranked as the 5th most significant problem out of the 12 main problems reported, with 28 responses (Table 1). In DM patients, pain was the 3rd most significant problem, tied with mobility issues with 15 responses.

Table 2 shows pain medication use in 1527 surveyed patients. Of these patients, 34% used some sort of pain medication, 23.5% used non-steroidal anti-inflammatory drugs (NSAIDs), and 4% used opioids.

Table 1. Most significant problems of disease for FSHD and DM (DM1, DM2, and DM-unknown) patients

	FSHD (n = 194)	DM (n = 177)	Total (n = 371)
Muscle weakness	94	84	178
Mobility	41	15	56
Disease progression	28	7	35
Muscle loss	28	7	35
Pain	**13**	**15**	**28**
Fatigue	3	17	20
Balance	3	9	12
Cardiac	1	9	10
Gastrointestinal	1	7	8
Psychiatric	0	6	6
Respiratory/Speech	2	4	6
Genetic	0	3	3

Table 2. Pain medication, opioid, and NSAID use in FSHD and DM (DM1 and DM2) patients

	FSHD (n = 575)	DM (n = 952)	Total (n = 1527)
Opioid use	38	23	61 (4.0%)
NSAID use	162	197	359 (23.5%)
Pain medication use	239	280	519 (34.0%)

Conclusion

Despite pain only ranking 5th in the most significant problem associated with their disease, it was still found to be more significant than other commonly-reported problems including fatigue, GI distress, and balance. The prevalence of pain medication use indicates that further studies relating to pain and the use of pain medications in this patient population are warranted. It can be concluded that DM and FSHD patients use NSAIDs less than the general population (23.5% vs. 37.5%) and use opioids more than the general population (4% vs. 2%).[6,7] Specifically, investigating questions about adherence, use, and beliefs toward pain medication will lead to an increased understanding of pain and its treatment in this patient population.

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