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Assessment of the Use of Non-Pharmacological Methods for Managing Depression in Patients with Myotonic Dystrophy (DM) and Facioscapulohumeral Muscular Dystrophy (FSHD)

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Assessment of the Use of Non-Pharmacological Methods for Managing Depression in Patients with Myotonic Dystrophy (DM) and Facioscapulohumeral Muscular Dystrophy (FSHD)

Abstract

Background: Myotonic dystrophy (DM) and facioscapulohumeral muscular dystrophy (FSHD) are two types of muscular dystrophies with multi-system manifestations.

Purpose: The purpose of this study was to determine 1: the prevalence of depression in patients with myotonic dystrophy (DM) and facioscapulohumeral muscular dystrophy (FSHD) and 2: which non-pharmacological methods DM and FSHD patients are using to manage their depression.

Methods: A survey was conducted using the online system, Qualtrics. The voluntary and anonymous survey was emailed to 1,205 eligible patients from the National Registry for DM and FSHD Patients and Family Members at the University of Rochester. Participants were at least 18 years old, a member of the registry, and diagnosed with DM or FSHD. The 65 question survey included questions on basic demographic information, depression diagnosis, medication use and effectiveness, and non-pharmacological management. Surveys were collected between May 2017 and August 2017 and the responses were analyzed and compared to the general population. The study was approved by the St. John Fisher College Institutional Review Board and the Registry Scientific Advisory Committee.

Results: Of the 1,205 surveys that were sent, 466 patients responded. A total of 46 percent of patients had DM (DM1 30 percent, n=138/460 and DM2 16 percent, n=75/460) and 48 percent (n=223/460) of respondents had FSHD. Of the study respondents, 34 percent (n=150/436) reported being diagnosed with depression, while 8 percent (n=24/294) feel depressed, but haven't been diagnosed. Non-pharmacological techniques used by patients who were diagnosed with depression or feel that they are depressed included: exercise (33 percent, n=57/150), relaxation techniques once per week (51 percent, n=50/98), and visiting a counselor or therapist once per week (11 percent, n=4/37). The most common type of relaxation technique used was meditation (52 percent, n=77/147) followed by yoga (18 percent, n=24/147). In conclusion, 32 percent (n=34/107) stated that relaxation techniques helped them, and 49 percent (n=52/107) stated that relaxation techniques may have helped them.

Conclusion: Patients with both DM and FSHD have been diagnosed with depression. To manage their depression, and similar to what occurs in the general population, DM and FSHD patients are using a combination of both pharmacologic and non-pharmacologic strategies. DM and FSHD patients also believe that these non-pharmacologic methods, which include exercise, counseling, and relaxation techniques are helpful in their managing depression.

Keywords

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Disciplines

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Comments

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8-282 Assessment of the use of non-pharmacological methods for managing depression in patients with myotonic dystrophy (DM) and facioscapulohumeral muscular dystrophy (FSHD)



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Background

Myotonic dystrophy (DM) and facioscapulohumeral muscular dystrophy (FSHD) are two forms of muscular dystrophy found in adults. They are characterized by weakness in the face, neck, hands, and shoulders, as well as multi-system complications¹. Many of these patients have been diagnosed with depression, and to manage this they are using both pharmacological and non-pharmacological techniques.

Purpose

The purpose of this study was to identify the prevalence of depression in this patient population and the medications and non-pharmacological techniques that patients use to manage depression.

Methods

Using the online system Qualtrics, an anonymous survey was created and sent to 1,205 eligible patients from the National Registry for DM and FSHD Patients and Family Members at the University of Rochester. To participate, patients had to be at least 18 years old, be a member of the Registry, and have been diagnosed with DM or FSHD. The survey included 65 questions on demographic information, depression, medication use and effectiveness, and non-pharmacological techniques. The survey was available from May 2017 to August 2017. All the information was kept anonymous. The study was approved by the St. John Fisher College Institutional Review Board and the Registry Scientific Advisory Committee.

Table 1. Demographic Information

Gender	DM1 (n=135)	DM2 (n=74)	FSHD (n=221)
Male	62 (46%)	27 (36%)	110 (48%)
Female	73 (54%)	47 (64%)	111 (50%)

Table 2. Age and disease state

Age (years)	DM1 (n=132)	DM2 (n=70)	FSHD (n=203)
18-24			2 (1%)
25-34	12 (9%)	1 (1%)	15 (7%)
35-44	35 (27%)	12 (17%)	22 (11%)
45-54	30 (23%)	17 (24%)	34 (17%)
55-64	36 (27%)	19 (27%)	65 (32%)
65-74	15 (11%)	19 (27%)	51 (25%)
75 and older	4 (3%)	2 (3%)	14 (7%)

Figure 1. Number of patients with depression

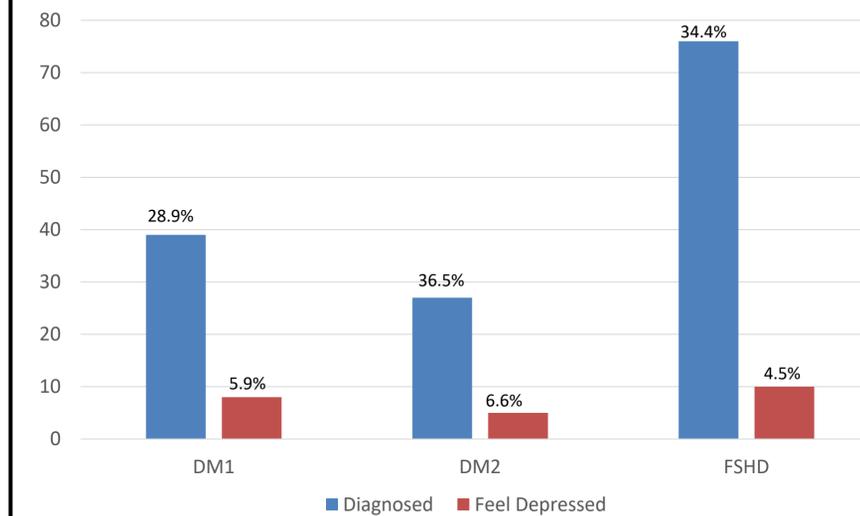
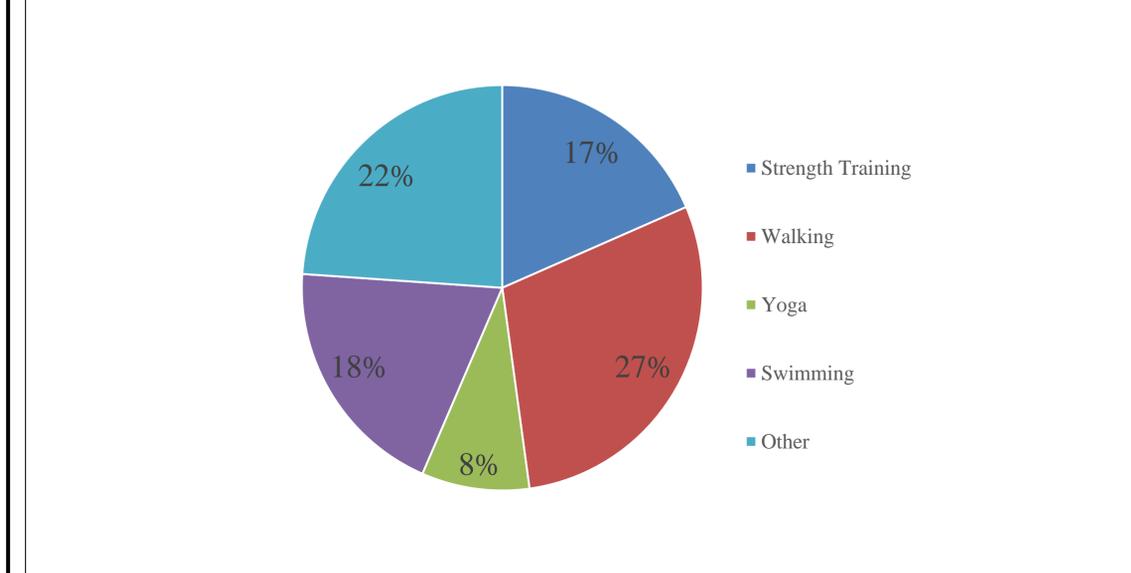


Table 3. Non-pharmacological techniques used

Technique Used	Patients using technique (n=173)
Exercise	57 (33%)
Meditation	77 (45%)
Counseling	27 (16%)

Figure 2. Exercise techniques used



Conclusion

Many patients with DM and FSHD have been diagnosed with depression. To manage this, patients are using both pharmacologic and non-pharmacologic strategies. It was found that their depression is being managed in a similar way to the general population². Patients are also widely using non-pharmacologic techniques which they believe are helping them in managing depression. To conclude, people with DM and FSHD utilize non-pharmacological techniques in the management of their depression in a similar way to the general population³.

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Nothing to disclose