



## Cannabis use in myotonic dystrophy patients in Germany and USA: a pilot survey

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Dear Sirs,

Myotonic dystrophies (DMs) represent the most common form of muscular dystrophies in adulthood. Both forms are characterized by a heterogeneous combination of muscular and multi-systemic symptoms, including weakness, myalgia, myotonia, early cataract, cognitive impairment and diabetes [1]. There is no causal therapy for these conditions and even the symptomatic treatment of some of the most disabling muscular symptoms, myalgia and myotonia, with several analgesics and anti-myotonic drugs is often unsatisfactory [2–4].

Studies on the use of both medical and non-medical cannabis/cannabinoids have shown some efficacy on chronic pain and spasticity [5]. However, the indication “chronic pain” is wide and pathophysiologically not well defined including different forms of pain (e.g. neuropathic pain, cancer-associated pain, headache, fibromyalgia, etc) which respond differently to cannabis use.

The pathophysiology of myalgia in DMs is still unclear and the potential therapeutic role of cannabis/cannabinoids in DMs patients has never been studied. Some patients refer, however, anecdotally to some improvement of symptoms under cannabis consumption. A pilot survey on cannabis use among patients with myotonic dystrophy has been, therefore, conducted in Germany and in the US. In order to maintain anonymity, the survey was sent through the German subgroup on myotonic dystrophy from the German society of patients with muscle disease

(DGM) and the Myotonic Dystrophy Foundation (MDF) to 591 and 3018 MDF members, respectively, per email and the completed questionnaires were sent back to us. Patients were asked to anonymously respond to the following questions: (1) general interest in taking medical cannabis for symptom’s relief; (2) the personal experience with cannabis; (3) the routes of cannabis administration; and (4) patient’s perceived efficacy of cannabis use on symptom relief (Table 1). The following areas of interest were explored for improvement: myalgia, muscle locking/myotonia, sleep quality, anxiety, appetite, mood and gastrointestinal symptoms. The response rate was 15.6% and 12.5% for the German and US surveys, respectively. However, about 5% of patients returned partially completed questionnaires. The median age range of responders was 41–50 (overall < 18 to > 60). The results of the survey are summarized in Table 1.

It has interestingly emerged that the vast majority of patients would like to try cannabis products or be included in future clinical trials, thus confirming the need for a better symptomatic treatment of muscular complaints. 14% of German patients and 33% of US-patients reported a regular consumption of cannabis/cannabinoids for symptoms relief. These patients have reported subjective improvements in different clinical domains (Fig. 1); especially myalgia and myotonia/stiffness improved in almost all patients. Only few and mild side effects were reported; however, the US survey did not seek details regarding the well-known side effects associated with cannabis consumption (Table 1).

From this pilot study emerges that DM patients are seeking cannabis to treat their muscular symptoms. There is, however, a high variation in the individual intake of cannabis and cannabinoids with respect to active components, frequency, dose and route of administration. An obvious limitation of this survey that it is self-reporting, which probably leads to an overestimation of the perceived efficacy [6]. However, a potential therapeutic effect of

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**Table 1** Characteristics of cannabis users among DM patients in Germany and USA

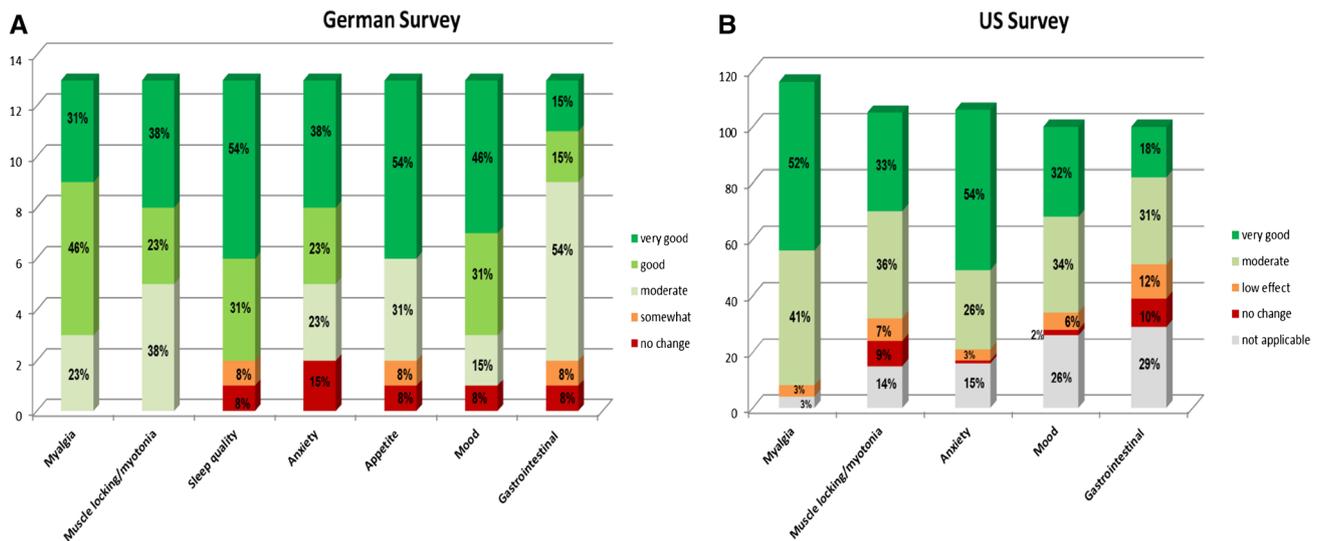
Surveys	Germany <i>n</i> (%)	USA <i>n</i> (%)
Sent surveys	591	3018
Response rate	92 (15.6%)	378 (12.5%)
Gender	<i>F</i> = 54, <i>M</i> = 38	<i>F</i> = 225, <i>M</i> = 153
DM Type	DM1 = 41, DM2 = 51	DM1 = 230, DM2 = 87 Unaffected family members: 61
1. Would you like to try medical cannabis for your symptoms?		
Yes	65	–
No	17	–
2. Are you currently taking medical or non-medical cannabis?		
Yes	13 (14%)	125 (33%)
No	79 (86%)	253 (67%)
3. For what reason are you taking cannabis/cannabinoids?		
Symptom's relief	10 (77%)	118 (94%)
Myalgia	7	101
Myotonia	4	63
Anxiety/depression	1	122
Gastrointestinal issues	1	41
Other	1	27
Recreational	3 (23%)	7 (6%)
4. Routes of administration		
Smoked	10	–
Evaporated	2	–
Oil	5	–
Spray	4	–
Capsules	2	–
Nutritional	4	–
5. Have you experienced any side effects while using cannabis/cannabinoids? <sup>a</sup>		
Yes	11	12 (10%)
Dry mouth	6	–
Red eyes	3	–
Increased appetite	6	–
Nausea/vomit	2	–
Dizziness	3	–
Headache	0	–
Cardiovascular problems	0	–
Other	1	–
No	2	106 (90%)

Questions no. 1 and 4 not included in the US survey

<sup>a</sup>Question no. 5 only allowed yes/no answers in the US survey

cannabis for myalgia and myotonia might be supported by the presence of cannabinoid receptors in muscles and by modulation of both central and peripheral pain pathways [7, 8].

In conclusion, these pilot data are highly evocative that cannabinoids should be systematically explored in a randomized clinical trial in patients with myotonic dystrophy of both types.



**Fig. 1** DM-Patients perceived efficacy of cannabis use in Germany (a) and US (b)

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### Compliance with ethical standards

**Conflicts of interest** FM, MW, AK, KS, SW have no conflicts of interest. BS is a scientific advisor of Nexien BioPharma, Inc.

**Ethical standard** This study followed the tenets of the Declaration of Helsinki. As this survey was a patient organization (MW, AK) driven survey, done anonymously and blinded, no formal IRB approval was submitted.

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