

Arthritis research

PARE0001

CANNABIS-BASED PRODUCTS FOR MEDICINAL USE: EXPLORING THE VIEWS AND EXPERIENCES OF PEOPLE WITH FIBROMYALGIA

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Background: A review by the Chief Medical Officer (CMO) of the United Kingdom (UK) in 2018 recommended moving cannabis-based products (CBP) from Schedule 1 of the Misuse of Drugs Regulations 2001 into Schedule 2, allowing CBP to be prescribed for medicinal purposes under controlled conditions by doctors on the Specialist Register of the General Medical Council. This prompted the National Institute for Health and Care Excellence (NICE) to develop guidance on prescribing CBP for medicinal use, which Fibromyalgia Action UK were invited to comment on. Anecdotally, we know that some people with fibromyalgia use CBP to help with pain relief; however, we wanted to explore these experiences further, while summarising people's thoughts of the draft scope guidelines.

Objectives: The aim of the survey was to understand experiences of CBP among people with fibromyalgia, including people's opinions of the NICE draft scope guidelines.

Methods: An online survey, hosted through Microsoft Forms, was disseminated via social media and Fibromyalgia Action UK's website between November and December 2018.

Results: A total of 69 people initially responded; with 66 eligible to participate. The average time to complete was 14:05 minutes. Over three-quarters (77%) reported using CBP. The types of CBP that people had used are shown in Fig 1. Over half reported using Cannabidiol (CBD)/Hemp oil (55%), currently marketed as a food supplement. Around one quarter (26%) used herbal cannabis, with few reporting use of plant-derived/synthetic delta-9-tetrahydrocannabinol (THC) or THC/CBD sprays (3-5%). Of the 50 who responded, 52% reported using CBP for medicinal purposes on a daily basis; 28% stated they used CBP during a fibromyalgia flare. While some people did not report any benefits, one of the clear benefits reported by people was pain relief. People also reported improved sleep and mood, less fatigue, and reduced anxiety. When asked to score the current NICE draft scope guidelines, 48 people responded, with an average rating of 3.88 (1=very poor; 5 = excellent). Some felt that the scope was quite vague, difficult to digest, unclear as to who should and shouldn't be prescribed CBP, and lacked specific reference to conditions like fibromyalgia. There were also concerns in the time it takes to develop guidance. When asked about confusion among society distinguishing CBP for medicinal purposes from food supplements marketed as CBD/Hemp oil, of 63 respondents, 86% felt there was confusion which needs addressing. Individuals felt that alternative treatment options like CBP should be available to people with fibromyalgia, with additional research to identify the evidence for its potential benefit and safety.

Conclusion: The survey highlights that people with fibromyalgia are using CBP, but not necessarily those that are prescribed by a medical professional. There is an appetite among patients with fibromyalgia to explore the option of alternative treatment using CBP. There is widespread confusion among society distinguishing CBP from CBD/Hemp oil marketed as food supplements, which could be leaving certain individuals vulnerable. The development of national guidance is welcomed; however, investment

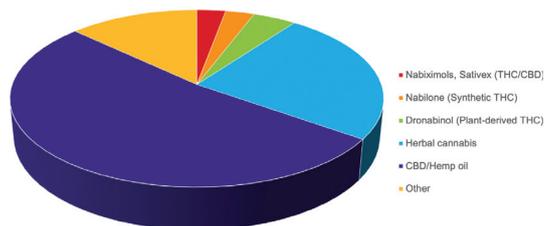


Fig 1. Types of CBP used by people with fibromyalgia in this survey.

in research to prove the efficacy and safety of CBP in people with fibromyalgia is also needed, to ensure that patients have appropriate access to safe treatments.

REFERENCES

- [1] Davies, S.C. "Cannabis Scheduling Review Part 1, The therapeutic and medicinal benefits of Cannabis based products – a review of recent evidence" London: Department of Health and Social Care (2018).

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Best practice campaigning

PARE0002

ME AND MY DILEMMA – A DANISH CAMPAIGN

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Background: The Danish Rheumatism Association wanted to raise awareness on the challenges people face on a daily basis living with an invisible disease like some RMDs. In addition, the fact that many people living with a RMD experience that their surroundings have a lack of understanding the daily struggles they have living with a chronic disease.

Objectives: We wanted to increase the general awareness of RMDs and to show our presence in another context than expected. In addition, the campaign should open up for some difficult talks in an entertaining way giving people an occasion to continue the talks at home. Finally the campaign should show that RMDs are not only related to old people and that consist of a wide range of diseases.

Methods: Through Social Media and our website and magazine we called for daily dilemmas from people with RMDs and their relatives, colleagues or friends. Having enough dilemmas, we set up four dilemma shows in malls across Denmark and invited to a public show 'Me and My Dilemma'. Four famous people were brought in to constitute the panel and discuss the dilemmas. A journalist, who is also radio and tv-host was appointed moderator and through 1½ hour he took the panel through hard, funny and emotional dilemmas and involved the audience in the discussions as well.

Results: 'Me and my dilemma' had a very broad appeal; it was entertaining yet serious and eye opening to both the panel and the audience. It gave The Danish Rheumatism Association an opportunity to tell many different stories about living with RMDs. Just getting the word out about a disease that rarely receives a lot of focus in the public.

We received about 100 dilemmas, most of them we had to moderate a lot in order to be real dilemmas that could be discussed, have pros and cons and also to make sure that there was a variation in age, gender, diagnose and subject.

Between 200-300 people attended each show, which was less than we expected, however Denmark experienced one of the warmest months of May ever and since the shows were planned inside the malls that explained the limited attendance.

The people who did attend the shows were all in the target group, having either a RMD or were related to someone with a RMD.

Conclusion: It was quite a bit of work getting the shows ready, but they fulfilled their purpose in raising awareness to the public and still reach our target group in a new way and in a new context.

By recording all the shows we were able to make 5 great podcasts on different dilemmas, which people with RMD and their relatives can relate to and discuss.

REFERENCES

None

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