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.

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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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Patient information and education

PARE0003 ESTABLISHING A PATIENT TRAINING CENTER OF RHEUMATOLOGY

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Background: Patient education is considered of pivotal importance for the Organization. Patients should be informed, educated and well trained to acquire the necessary skills needed to deal with the challenges of living with a chronic disease. Equally important is the need of patients to acquire certain skills, necessary for advocating for their rights and representing their Organizations, both at the National but also at the European level. Realizing the above issues, the National Organization decided to create this training centre at its own premises, as it was noted that there was a lack of expertise in the above area, and that patients needed to be empowered to be equal partners in health decisions, but also effective Self managers of their condition.

Objectives: One main objective is to educate individual patients to Self manage their disease by accepting the new situation in their life, but also by learning how to effectively communicate with HPs, to be adherent to treatment, to cope with family work and social environments, and to regain self –confidence. The other objective is to train expert patients, enhance their knowledge and empower them for representing the Organization on all relevant Health committees and participate on all stages of the decision making process.

Methods: First step was to create a Brand name and acquire the relevant certificate of the establishment of the training centre. After the certification process had been finished, two volunteers from the Organization were trained by the National Authority of Human Resources and after successfully passing the 8-hour examination, they became certified trainers. A committee, under the two coordinators is now in the process of revising the modules of the first 5 courses which are offered initially, by restating the aims and objectives of each course as well as the training procedure, teaching techniques, methods and evaluation process. The courses are: The self-management (running), the expert patient (running) Self Diagnosis (running), Training for parents of Children with Rheumatic diseases (Coming before the end of Year), "Rebuilding the story of our life" –Systemic Sculpture method (Running from October 2019- April 2019)

The plans for the next steps include the creation of training course on building patient advocacy skills (Participation in Health committees, HTA, Advisory committees etc) and one on recruiting and training of volunteers.

Results: The experience from the implementation at the initial stage of the three training courses (Self-management, expert patient and self-diagnosis) shows that patients are happy to join, to share experiences and feelings and they successfully attempt to use the skills acquired in their everyday life. Some of the Organization's members have now become members on National Health committees. These include the Committee for Pricing of Medical products, National Health Insurance, ad hoc for updating the rights of patients, rare diseases, for digital Health etc. Success of the existing modules has led the Organization to decide on building an online portal for digital learning.

Conclusion: The creation of a rheumatology training centre for patients, although at its initial stage, has shown positive results for patients, by enhancing their ability to deal in an effective way with the chronic disease but also in improving their skills and knowledge to strive for effective advocacy and for being part of all in decisions that affect their rights in health.

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Best practice campaigning

PARE0004 EASY TO OPEN/EASY TO USE: ACCESSIBILITY FOR PEOPLE WITH REDUCED HAND FUNCTION

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Background: One fifth of Sweden's population, more than 1.5 million people, has reduced hand function.^[1] For the European population, it would equal well over 60 million people.

People with reduced hand function, for example due to illness or age, are often unable to handle products or packaging without additional daily living aids. In addition to the 20 percent of the population with reduced hand function, often due to rheumatic disease, women on average have 40 percent lower hand strength than men. In other words, the market for inclusive design is huge and concerns a large portion of all consumers.

The Swedish Rheumatism Association, SRA, has for many years fought for accessibility of products and services for our members. The SRA has a history spanning over 15 years of activism for inclusive design. The highlight being the launch of the universal standard *SS-ISO 17480:2015 Packaging - Accessible design - Ease of opening*, of which the SRA was a big contributor. However, the aim for this abstract is not to put emphasis on previous successes but to describe current attempts to make the packaging industry adapt a more inclusive design for the many people with reduced hand function.

Every third year thousands of delegates visit Scanpack, Northern Europe's biggest packaging fair. Last year was the first time the SRA attended as an exhibitor, making the SRA the only non-profit organisation working for people with rheumatic diseases, to participate. 463 exhibitors from around 30 countries attended, with 16,500 delegates in total, of which 12,900 were visitors. The fair took place on October 23-26, 2018 in Gothenburg, Sweden.

Objectives: "Products that are functional and easy-to-use for people with reduced hand function, are suitable for everyone". This tagline defined our work for inclusive design. We focused on three objectives in order to make more visitors at the fair aware of the benefits with inclusive design on packages and products. We addressed the packaging industry, the pharmaceutical industry and those who produce products for the public environment. These were the objectives:

- Everyone should know that it is possible to measure manageability.
- Everyone should know that help is available. Tests apply to all types of products and packaging.
- Everyone should know that there is an "Easy to use" and "Easy to open" seal of approval available for packages.

Methods: At the fair, the SRA showed and told visitors how tests on manageability were done, and offered companies to do our small-scale tests of their products. We showed examples of packages that were approved with our certification method. The visitors were also encouraged to participate in our questionnaire.

The questions they had to answer were:

1. How many percent suffer from reduced hand function in Europe? 52 percent of the survey responses were correct. Correct answer: about 20 percent.
2. Women have weaker hand strength, compared to men. How much weaker? 56 percent of the survey responses were correct. Correct answer: 40 percent.

328 people participated in the survey.

Results: Representatives from leading packaging companies and visitors at Northern Europe's biggest packaging fair lack insight in the extent of reduced hand function in Sweden.

Half of the participants who visited the SRA's exhibition responded correctly to our questionnaire regarding reduced hand function, suggesting there is room for improvement in the packaging industry to adapt a more inclusive approach towards design that benefits people with rheumatic diseases.

Conclusion: Half of the participants who visited the SRA's exhibition responded correctly to our questionnaire regarding reduced hand function, suggesting there is room for improvement in the packaging industry to adapt a more inclusive approach towards design that benefits people with rheumatic diseases.

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