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Community nurses' support for patients with fibromyalgia who use cannabis to manage pain

Phillips, A. and Andrews, N.

How can community nurses support fibromyalgia patients who use cannabis to manage pain?

Abstract

Supporting patients to manage chronic pain conditions such as fibromyalgia (FM) remains a challenge for community nurses. Research suggests that despite the absence of a licensed cannabis-based medicinal product (CBMP) available for people with FM in the UK, there is an appetite for FM patients to use cannabis for pain management. Nurses have expressed anxieties when balancing tensions between helping patients and working within medical guidelines, as well as a need for further education about patient cannabis use. This article provides community nurses with insight into how cannabis use affects the pain experience for people living with FM. Despite potential harms, cannabis is perceived by users to have a positive impact on the lived experience of pain, and it may be preferred to prescribed opioid medication. This understanding can help to inform empathic practice and recommendations are made for reducing the risks of cannabis use to patient health.

Keywords

Fibromyalgia, pain, cannabis, community nursing, lived experience, harm reduction.

Fibromyalgia (FM) is a chronic illness characterised by a dominant feature of widespread pain that lasts for at least three months (Fayaz 2016). Additional symptoms may vary, but typically include fatigue, non-refreshed sleep, disturbances in mood and cognitive impairments (Macfarlane et al. 2016). As this condition is complex to diagnose, the prevalence of FM in the United Kingdom (UK) is unclear, however, estimates suggest that this is likely to affect between 2% (Queiroz 2013) and 5.4% of the population (Jones et al. 2015). FM diagnoses in the UK are higher in women than men, tend to peak in patients aged between 30-59 years and occur amongst those from the poorest social backgrounds (Collin 2017). To the present day, the causes of FM remain incompletely understood; nevertheless, the pain and suffering experienced by those diagnosed with FM is very real and debilitating:

'I attempted suicide… It's just going to get worse and worse and worse and living with that feeling and the knowledge that there's nothing I can do that makes it better… the only way I can't be like this is to be dead.' (Ashe *et al.*, 2017, p. 8).

Patients report that the condition impacts on all aspects of life, including work, social relationships, leisure and optimism about the future (Wuytack and Miller, 2011).

As there is no known cure for FM, symptoms must be carefully managed to enhance quality of life (Rahman et al. 2014). A variety of different pharmacological agents have been recommended to manage the chronic pain symptoms and these include but are not limited to: anticonvulsants, antidepressants and weak opioids such as tramadol (Franco et al., 2010). The treatment of FM remains a challenging issue for both patients and practitioners as opioids are prescribed frequently, despite a lack of evidence of their efficacy in this context (Davis *et al*., 2017). Evidence suggests that patients are likely to require combinations of pharmacotherapies to alleviate symptoms and it is acknowledged that there is a need to develop new drug treatments for this condition (Northcott et al. 2017).

The lack of efficacy of pharmacological drugs has meant that discussions concerning alternative treatments such as cannabis have become increasingly relevant (Shah et al. 2017). In some states in the United States (US) where medical cannabis has become widely available, patients have turned to this means of managing their pain, reporting a reduction in symptoms, decreases in use of medication and reduced side effects (Boehnke et al. 2016). In Britain where medical cannabis is not routinely offered, an estimated 1.4 million people, 2.8% of the population, are using illicit cannabis for the symptomatic relief of a medically diagnosed condition (Couch, 2020). This clear appetite for cannabis to address symptoms such as chronic pain poses challenges for front line health care professionals who are expected to respond to patient need, but are not provided with clear standards for helping their patients to use cannabis safely and effectively (Schlag et al. 2020).

Within this uncertain landscape, significant practice challenges are posed for nurses who want to help patients with long-term conditions but are anxious about 'doing the wrong thing'; thus the Royal College of Nursing (RCN) are taking the lead in medical cannabis reform, supporting an approach that emphasises evidence-based education to facilitate confident conversations with patients (Stephenson, 2019). It has been found that educating community nurses about the lived experience of cannabis use in multiple sclerosis (MS) sufferers can help to build trusting relationships with the patient that can dismantle stigma (Daly et al. 2019). Community nurses are required to diminish the suffering of their patients who experience chronic pain and central to the success of this, is an approach that proactively seeks to understand the subjective experience of the patient (Ongston-Tuck, 2012). Therefore, this article aims to inform the practice of community nurses by providing insight into the lived experience of cannabis use in chronic pain sufferers. From this, suggestions are made for how community nurses can best reduce harms and promote the health of FM patients in order to increase their quality of life.

Cannabis use and fibromyalgia pain management

'Cannabis' is a term that broadly describes products derived from the Cannabis sativa plant that may be used for medical, recreational and industrial purposes (National Academies of Sciences, Engineering and Medicine (NASEM) 2017). There are in excess of 500 components contained within cannabis, but two primary chemicals have been the subjects of scientific investigation because of their effects on the human body: tetrahydrocannabinol (Δ9-THC) and cannabidiol (CBD) (Lafaye 2017). THC is the psychoactive component of cannabis that provides users with feelings of euphoria and pleasure, while CBD has demonstrated anti-epileptic, anti-inflammatory and pain-relieving properties. Furthermore, the different effects that cannabis has on the body when the THC to CBD composition ratios vary is a subject for further research. Cannabis takes several forms, such as herb, resin or oil and can be consumed through smoking with tobacco, the use of bongs, edibles and vaping (National Centre for Smoking Cessation and Training (NCSCT), 2020). Figure 1 summarises the most common types of cannabis in the UK and explains how they are used:

Figure 1: A summary of the most common types of cannabis used in the UK (NCSCT, 2020, p. 5)

TYPE OF CANNABIS	IN A NUTSHELL	COMBUSTIBLE	NON-COMBUSTIBLE
Seeded herbal cannabis (Dry herb)	Commonly referred to as weed, grass or herb. The dried flower/leaf can be smoked (usually combined with tobacco) or vaporised in a small portable device similar to an e-cigarette, or in larger non-portable vaporisers.	✓	✓
Seedless herbal cannabis (Sinsemilla)	Commonly called skunk. Has been grown in such a way as to increase the THC content. Commonly smoked with tobacco or vaporised.	✓	✓
Resin, hash or solid	Cannabis compounds are extracted from the plant, and formed into a compressed block. Commonly smoked with tobacco.	✓	✓
Concentrates (Shatter, wax, butane hash oil)	THC is extracted from the plant using highly efficient processing methods (e.g. butane or carbon dioxide) to increase concentration. The concentrate may resemble wax, or even toffee brittle, and is consumed by heating to a high temperature on a nail or similar heated element and inhaling the vapour – a process known as dabbing. Concentrates are less common in the UK.	✓	✓
Cannabis oil	By using solvents or gases to create a solution which is then heated, oil can be extracted from the cannabis plant. The oil may contain THC, CBD or both; it can be used in edibles or could be added to liquid and used in an e-cigarette (see PHE advice on page 12 for associated risks).		✓
Edibles	Cannabis may be mixed in food, such as brownies, or even drink. This is usually resin, although other forms including tinctures may be found.		✓

Cannabis for non-therapeutic use is presently classified as a class B drug under the Misuse of Drugs Act (1971), whereby penalties for its possession are a maximum of five years in prison, a fine or both. Previously to November 2018, cannabis was a Schedule 1 drug in the UK under The Misuse of Drugs Regulations (2001), which meant that its possession and supply were prohibited without Home Office approval, including for medical purposes. Further to highly publicised pressure from patient groups and lobbying in favour of decriminalising cannabis for medicinal use from the Royal College of Nursing (RCN) Congress (RCN Bulletin 2018), cannabis-based products for medicinal use (CBPM) were rescheduled to Schedule 2, allowing them to be available for research and prescribing (House of Commons Health and Social Care Committee, 2019). CBPM include any preparations or products intended for medicinal use in humans that contain cannabis, cannabis resin or a cannabinol derivative (The Misuse of Drugs (Amendments)

(Cannabis and Licence Fees) (England, Wales and Scotland) Regulations 2018). At present, there are two CBPM available for prescription in the UK: Epidyolex, an orally administered CBD treatment for rare forms of epilepsy in children, and Sativex, an oral CBD/THC spray for the treatment of spasticity in MS (Freeman et al. 2019).

While there is evidence for the effectiveness of cannabis in treating chronic pain and sleeping problems for people with FM (NASEM (2017), the overall evidence base lacks the robustness required for approving the prescribing of CBMP for patients with chronic pain conditions, including FM (National Institute for Health and Care Excellence (NICE) 2019). Consequently, NICE have been unable to endorse the prescribing of CBMPs (including CBD) for FM, but have recommended that due to the significant population of chronic pain sufferers in the UK population and the severity of symptoms, further research should explore the clinical and cost-effectiveness of these treatments. The subsequent difficulties that chronic pain sufferers have experienced in trying to gain access to CBMPs has left many patients left feeling disappointed and let down:

> *"We feel like we've been robbed. This is not the medical cannabis that we've been campaigning for. It's a sleight of hand"* (Hurley, 2018, p. 1)

Unfortunately, there are a lack of studies that investigate the efficacy and safety of cannabis in patients with FM and those that do exist do not possess the methodological strengths required to generalise findings (Cameron and Hemmingway, 2020). Nevertheless, there are several smaller-scale, in-depth qualitative studies that explain the lived experience of cannabis use in FM and chronic pain sufferers and it is useful for health professionals to consider these perspectives while the evidence base is being developed further.

Patients' perceptions of the benefits of cannabis use for pain management

Reduced pain symptoms

While self-report studies are entirely subjective and may not accurately reflect public opinion or the wider evidence base, they can provide a nuanced understanding of the pain experience and insights into FM patients' perceived costs and benefits of cannabis use (Piper et al. 2017). Some

FM patients have reported that their pain manifests in 'flares', an increased feeling of unbearable pain intensity that is accompanied by a full-body aches and exhaustion (Vincent et al. 2014). One chronic pain sufferer in the US reported that the thing they most liked about medical cannabis was the relief of having a break from this pain:

> *"I feel no pain…anyone who hasn't had chronic pain would not even understand how good it feels to even have it gone for a few hours."* (Piper et al. 2017, p. 4)

Similarly, an Israeli qualitative study conducted using chronic pain sufferers using medical cannabis found that participants placed a high value on the 'sigh of relief' created by the reduction of pain (Lavie-Ajayi and Shvartzman 2019). Cooke et al. (2019) found that for chronic pain sufferers, pain management is central to daily life and some patients report that cannabis is the only thing that has offered any kind of reprieve from this constant preoccupation.

Increased control over daily functioning

It is important to note that the pain experience for those with FM includes both physical and mental distress (Galvez-Sánchez et al. 2019). Furthermore, the sense of helplessness that this condition creates can reduce patients' ability to adapt to the disease. People living with FM have described that their condition has left them with a sense of loss of activities, relationships and professional achievements that is accompanied with feelings of great sadness and disappointment:

> *"To me fibro robbed me of my dreams… Both my pain and my tiredness has an impact on me. It stops me being who I want to be."* (Brown 2018, p. 9)

Lev and Goldner (2020) demonstrated that women with FM were strongly motivated to exert control symptoms and achieve personal career goals, particularly as they were often accused of laziness. However, they were often exhausted by the efforts to maintain normalcy and it was recommended that people with FM need support to maintain their careers. A qualitative study that investigated the impact of supervised medical cannabis use in Israel on the cognitive, social and psychological dimensions of chronic pain, demonstrated that despite side effects, cannabis

enabled patients to gain a sense of 'a restored self', through the increased enablement to perform normal daily functions, sleep and focus their mind (Lavie-Ajayi and Shvartzman 2019).

Reduced use of opioid medication

Some evidence suggests that medical cannabis can help chronic pain patients to reduce their use of opioid medication (Boehnke et al. 2016, Centre for Medical Cannabis 2019). One possible explanation for this concerns the management of the respective availability of each drug. For example, a qualitative study in the US found that chronic pain patients perceived that one benefit of using cannabis alongside opioids was that when an opioid prescription could not be obtained, cannabis could be used as a substitution to manage pain (Cooke et al. 2019). Another reason is that cannabis may enhance the ability of opioid drugs to relieve pain so that a lower opioid dose is required for the same analgesic effect, a phenomenon that has been termed the 'opioid-sparing effect' (Nielson et al. 2017). A potential advantage posed by substituting opioid drugs for cannabis when patients are using illicit drugs to manage pain, is that the risk of overdose from cannabis is very small in comparison to the risk of opioid overdose (World Health Organization, 2016). Another reported benefit is that cannabis can help users to be more engaged with their children (Peters 2013) and ease the unpleasant side effects of opioid medication, which include constipation, nausea and withdrawal (Reiman et al. 2017). Importantly, some patients in this latter study highlighted that pain symptoms varied on a day-to-day basis, so co-use helped them to manage days when the pain felt more intense.

Patients' concerns: gaining access to treatment

Due to the lack of legitimate access to CBMPs in the UK, people with FM are gaining access to them from sources alternative to a medical professional (Stones and Quinn, 2019). There are subsequent concerns that people in pain will be diverted to sourcing illegal cannabis through the black market, be exposed to products that have not been tested and approved and be regarded as a criminal for wanting to relieve their pain and suffering (Stevens, 2018). Indeed, several high-profile case studies relating to this have been hotly debated within mainstream media in the UK. For example, medical cannabis law reform advocate Carly Barton, who suffered a stroke in her

twenties that left her with fibromyalgia and constant pain, has publicly challenged the barriers to gaining an NHS prescription for a CBMP (Sky News 2018, Mahase 2019). Ms Barton was initially gaining access to cannabis on the black market, but this left her feeling highly vulnerable to arrest or being physically attacked. Although she was legally prescribed cannabis by her private consultant in April 2019, this left her facing costs of £2,500 for a three months' supply. Her substantial campaigning has led to the development of a 'Cancard', a holographic ID card that will be available from 1st November 2020 for the estimated 1.1 million people who quality for a private CBMP prescription, but are unable to afford the cost (Cancard, 2020) The card will not legally entitle patients to cannabis, but it provides evidence of a mitigating factor within the Crown Prosecution Service. Further information and application forms are available online at: www.cancard.co.uk.

Implications for practice

The use of cannabis with other medication indicates that patients demonstrate they are using cannabis as a personal method of harm reduction (Vigil et al. 2017). A harm reduction approach is one that accepts drug use as an enduring feature of people's lives, prioritises goals based on individuals' needs, maintains dignity and respect for people who use and focuses on reducing harms from drug use, rather than ceasing use (Lenton and Single, 1992) Community nurses can adopt this approach when working with FM patients who use cannabis, by being non-judgemental about use, discussing how its use is embedded in patients' lives and considering how harms can be reduced. The Cannabis Patient Advocacy and Support Services (CPASS), founded and chaired by former community district nursing sister and Health Minister Ann Keen, is a collaborative organisation that seeks to provide support, advocacy and education to patients and healthcare professionals (CPASS 2019a). CPASS (2019b) have produced a medical cannabis guidebook for patients that provides practical guidance about how the risks to health can be reduced. These are summarised in figure 2 (with an acknowledgement that patients may be using illicit street cannabis). Any regulated healthcare professional who wishes to increase their knowledge and confidence when working with medical cannabis patients can register with the

Sapphire Institute for Medical Cannabis Education and gain access to free e-learning modules: https://www.sapphirefoundation.co.uk/

Figure 2: How to reduce the risks of cannabis-related harms to health (based on the recommendations in CPASS 2019b).

SOURCE OF HARM	HOW TO REDUCE THE RISKS
Cannabis	If patients choose to use cannabis to manage their pain, they should be aware of the potential health risks: • **Side effects:** increased heart rate, feeling dizzy, impaired coordination and reaction times, drowsiness, short-term memory impairment, dry mouth, nausea, anxiety, respiratory irritation (if inhaled), increased appetite, and euphoria. • **Withdrawal symptoms:** if a patient ceases use or uses infrequently, they may experience withdrawals. These can include: increased dreaming/nightmares, sleep disturbances, changes in appetite, headache, irritability and mood changes. Patients are advised to keep a use diary to monitor symptoms and side effects, so that they can use an informed trial and error system of symptom control.
Route of administration (way into the body)	Inhaling cannabis using a vapourizer (heating it without burning) and ingestion (e.g. oils or baked into food) are less harmful than smoking cannabis with tobacco. The significant health harms from tobacco use can be avoided if the patient changes to another route of administration.
Dose	*"Start low, go slow"* – it is advised that patients start with 1 inhalation and wait 15 minutes before using more, observing how symptoms change throughout. This principle is even more important when cannabis is being ingested, as the effects of cannabis can take 1-3 hours to set in and can last longer than when inhaled.
Interactions with other drugs	Cannabis can interact with other illicit drugs, alcohol and prescribed medication. Careful consideration should be given to other depressant drugs, such as alcohol and opioids, as when used together the central nervous system will be slowed down even more.
Contaminated sources	Illicit cannabis is more likely to be contaminated with moulds, pesticides and other substances. This should therefore be gained from as trusted a source as possible.
Increased risk of accidents	• **Responsible storage:** like any drug or household chemical, cannabis products should be stored away from children and pets, in clearly labelled packaging. • **Do not operate machinery** whilst under the influence of cannabis. • **Do not drive whilst under the influence of cannabis:** The UK government operate a 'zero tolerance' approach to driving under the influence of illegal drugs and a driver found with more than 2 microgrammes of THC per litre of blood can face penalties of a minimum 1 year ban, an unlimited fine, up to 6 months in prison and an illegal record (Department for Transport, 2017). However, if

	patients are taking medicine as prescribed and it does not impact their driving, then they are within the law. Patients should be advised that if they are in any doubt about their ability to drive, they should not. Further information and resources for health professionals, including an advice leaflet that can be shared with patients can be found here: https://www.gov.uk/government/collections/drug-driving#information-for-healthcare-professionals.
Legal issues	• Consider a Cancard application. The card comes with an information resource pack. • Know the rules for travelling with cannabis. Further information can be found here: https://www.gov.uk/travelling-controlled-drugs

Conclusion

This article provides insight into the lived experience of pain for people with FM and explains how cannabis use can help to alleviate symptoms and improve quality of life. As CBMPs are not readily available for people with FM in the UK, patients are resorting to gaining access to these through sources alternative to a health professional, including the black market. This complex situation provides uncertainty for nurses who want to help their patients and reduce harms to health. Nevertheless, understanding patients' lived experiences and adopting a harm reduction approach can help to reduce stigma and support people with FM to establish control over their lives. Further education and training are now available online for community nurses who wish to increase their knowledge and confidence when working with patients who use cannabis for the management of their pain.

Key Points

- Fibromyalgia (FM) is a long-term condition characterised by widespread pain that is complex to diagnose and difficult to treat and manage.
- People with FM have reported that cannabis and cannabis-based medical products (CBMPs) can be beneficial in managing their pain symptoms, but these are difficult to access.
- Research studies that examine the subjective experiences of people with FM who use cannabis for pain management can provide community nurses with insight into patients' lives and enhance person-centred working practices.
- Through adopting a harm reduction approach that emphasises personal autonomy, community nurses can work with patients to identify practical solutions that reduce the potential harms associated with cannabis use.

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