

A Clinician Survey of Use Assessment, Documentation, and Education about Cannabis Use in Persons with Cystic Fibrosis

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Keywords: cannabis, cystic fibrosis, documentation, education

1) Abstract

Introduction: To help open the clinician dialogue regarding cannabis use in persons with CF in the U.S., we aimed to describe current practices of use assessment and documentation processes related to cannabis.

Methods: A cross sectional, anonymous survey study was distributed via email to CF directors and coordinators and to the Cystic Fibrosis Foundation (CFF) listservs of nurse, pharmacist, dietitian, social worker and psychology care team members. The survey tool included multiple choice, scaled and open ended items, which assessed participants' awareness of current cannabis laws in their state, prescribing practices for medical marijuana, screening and documentation practices, knowledge of and what indications participants believe cannabis and cannabidiol (CBD) could be beneficial. Data was analyzed using descriptive statistics.

Results: There were 282 survey participants, with majority as providers (28%) and social workers (29%), representing all U.S. regions. Participants varied in terms of frequency of evaluating cannabis use, with 15.4% "always," 48.4% "sometimes," and 41% "rarely" or "never" asking about it. Regarding recreational versus medical cannabis use, 55.4% and 62.5% reported documentation of each type in the medical record, respectively. Participants reported appetite, pain, and nausea as the top three advocated indications for use. About 35% and 72% of participants felt "slightly" or "not at all" prepared to answer patient/family questions about cannabis and CBD, respectively.

Conclusions: The approach to cannabis use assessment, documentation, and education across CF care centers is variable. There is a need for care team and patient/caregiver education materials about cannabis/CBD and CF.

Introduction

The role of cannabis in healthcare remains relatively controversial with complicated legal statuses and lack of safety and efficacy data in specific chronic diseases, such as cystic fibrosis (CF). Given the multi-organ system manifestation of CF, persons with CF may consider complementary alternative medication or treatment as part of daily care, including cannabis or cannabidiol (CBD) products.

As cannabis has become more available and marketed, persons with CF may utilize it as self-treatment for many symptoms of CF, such as appetite, pain, or mental health concerns. As CF is a disease that affects the lungs, inhaling cannabis may potentiate lung insult and should be avoided. Repeated inhalation of cannabis can cause chronic bronchitis, airway inflammation, edema, loss of cilia, and goblet cell hyperplasia leading to increased secretions.¹⁻³ However, cannabis inhalation via smoke or vaporizers is likely the most readily available and inexpensive for consumers.^{4,5} Edible and topical versions may be more cost prohibitive, leading to more accessibility of inhalational forms of cannabis.

Clinician guidance related to cannabis and/or CBD products are currently limited. For example, at the time of this manuscript, there were no available educational documents or guidelines regarding cannabis from the CF Foundation. Cystic Fibrosis Canada published a position statement in October 2018 recommending that cannabis “should not be smoked, vaporized or inhaled in any way. Further, second-hand cannabis smoke is to be avoided.”⁶

Cannabis is currently illegal under federal law in the United States and is a Schedule 1 substance per the Controlled Substances Act of 1970. Despite federal illegality, cannabis has been legalized for medical and/or recreational use at the state level. California was the first state to legalize medical use in 1996. As of 2021, 36 states and the District of Columbia have legalized medical use of cannabis.⁷ Cannabis was first legalized for recreational use in 2012 and is currently legal for both recreational and medical use in 15 states and the District of Columbia. In 11 states where there is no medical cannabis program, CBD/low tetrahydrocannabinol (THC) products are legal. Three states currently maintain illegality for all forms of cannabis.

In 2018, the US Food and Drug Administration (FDA) approved a new drug, Epidiolex®, a pharmaceutical grade CBD solution. This oral medication contains 98% CBD and was approved for patients at least two years of age with intractable seizures associated with Lennox-Gastaut syndrome or Dravet syndrome.⁸ This product has not been evaluated in people with CF.

As research interest in cannabis and its chemical components continues to advance and as accessibility of cannabis and CBD widens, it is prudent to include CF in the conversation. Our objectives were to open the dialogue regarding provider views on cannabis use amongst the United States CF population, and evaluate whether care providers are assessing for and documenting cannabis use. Based on information collected from this survey study, we hope to inform and encourage development of education materials for medical providers and people with CF.

Materials and Methods

A cross sectional, anonymous survey was distributed by the Cystic Fibrosis Foundation via email to 328 CF Directors and 299 center coordinators, which represented physician and nursing disciplines, at accredited CF centers in the United States from October through November 2018. The survey was also distributed to RN, pharmacist, dietitian, social worker and psych CF Foundation listservs. Participants were clinicians from pediatric and adult CF care centers. After an initial email distribution, a reminder email was sent halfway through the study period. The 31-item survey tool utilized skip and branching logic comprised of multiple-choice, multiple-select, Likert scale, and open ended items. The survey assessed participants' awareness of current cannabis laws, reported prescribing practices for medical marijuana, whether patients are regularly screened for cannabis use as part of CF care, and perceptions regarding potential health benefits of cannabis. It also assessed knowledge of cannabis and CBD and for which areas caregivers would like educational materials.

This project received IRB exemption at Oregon Health and Science University. Study data were collected and managed using REDCap electronic data capture tools hosted at Oregon Health and Science University. REDCap ^{9,10} (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. Descriptive statistics were used including Chi square, Fisher Exact, and Kruskal Wallis tests, with alpha priori of 0.05, using STATA SE 16.0 (College Station, TX). "Yes"/"No"/"I don't know" results were dichotomized (to "Yes" and "No/I don't know") for statistical analysis. Open-ended question responses were reviewed for themes.

Results

There were a total of 282 survey participants, the majority of which were providers and social workers, 28% and 29% respectively (**Table 1**). Participants embodied pediatric, adult, and combined population clinician types. All U.S. regions and center sizes ranging from less than 100 to over 300 patients were represented.

Perceived Cannabis Legal Status and Prescribing Practice

When participants were asked about the legality of medical cannabis use, 57% stated that it was legal in their state. When asked about recreational cannabis use in their specific states, 81% of participants reported that they did not think or know if recreational cannabis was legal in their state (**Table 2**). Of the 36 responding providers, 86% reported that they have not prescribed cannabis to patients. If cannabis was legal, 20% reported they would prescribe (**Table 2**).

Evaluation of Use - Cannabis

When asked about how often they asked patients about cannabis use, only 15.4% of participants stated “always” whereas many (48.4%) stated they “sometimes” asked (**Table 3**). There was a significant difference between disciplines about how often they asked about cannabis use with their patients ($p=0.0001$), with the greatest proportion of social work participants (78.6%) reporting they either “always” or “sometimes” ask. Participants also reported that the top disciplines that should and do ask about cannabis use are physicians, nurses, and social workers (**Figure 1**). Although evaluation of use appears to be inconsistent, once participants learn of use, it appears they are consistent with asking subsequent questions to better understand patients’ use. When a patient is known to use cannabis, 68% “always” ask about reason for use and 85% ask about method (e.g., smoke, vape, edible, topical) of use. About 75% of participants report “always” asking about frequency of use when a patient reports use (**Table 3**).

Documentation of Use - Cannabis

Reported team documentation of recreational cannabis use in the medical record was significantly different between care disciplines, with nearly 70% of providers and 67% of nurses report team documentation of use ($p=0.002$) (**Table 3**). Overall, 55.4% of participants reported that their team documents use of recreational cannabis in the medical record. A greater proportion of providers (88.6%, $p=0.001$) reported team documentation of medical cannabis use compared to other disciplines. About 63% of all participants report team documentation of medical cannabis use in the medical record. The most commonly reported locations of recreational use documentation were social history and encounter documentation, whereas medication list and encounter documentation were most common for medical cannabis use (**Figure 2**). Of participants who reported not documenting recreational (44.6%) cannabis use, the most common primary reason reported was uncertainty of where it should be documented, followed by concern for future transplant candidacy. For those who reported not documenting medical cannabis use (37.5%), the primary reason varied including uncertainty of where it should be documented, concern for transplant candidacy, stigma attached to patient (**Figure 3**).

Education - Cannabis

When it is determined that a patient is using cannabis, about 67% of participants educate about risk or side effects of cannabis use (**Table 3**). Interestingly, only 25.5% of participants felt “extremely” or “very” prepared to answer patient/family questions about cannabis and CF. The overwhelming majority of participants wanted some kind of education material with only three respondents reporting they did not want any (**Figure 4**). The top three areas of education requested by participants were data regarding indications for use (e.g. pain), risk/side effects of cannabis use, and THC versus CBD effects.

Perspectives About Indications for Cannabis

Participants were also asked to provide feedback about which indications they would support use of cannabis or CBD. The top three reported indications for advocating cannabis use were appetite, pain, and nausea (**Figure 5**). The most commonly stated reasons participants would not support cannabis use in persons with CF were concerns over future lung transplant exclusion, federal illegality, and concern for addiction (**Figure 6**).

Cannabidiol (CBD)

When asked about CBD legality for medical use in their state, nearly 56% of participants believed it was legal (**Table 4**). Only 35.7% of participants would support off label use in CF of prescription CBD oral solution (Epidiolex®, Greenwich Biosciences). Most participants (72%) felt they were “slightly” or “not at all” prepared to answer patients' questions about CBD and CF. When the participants were asked about how knowledgeable they were about CBD versus THC, 68% stated they were “slightly” or “not at all.” About 59% reported that they “never” talk with patients regarding the effects of CBD versus THC. The top three reported indications for advocating CBD use were pain, appetite, and anxiety (**Figure 5**). A greater number of participants (97 vs 31) were not sure what indications they would advocate for CBD versus cannabis in CF.

Review of Open-Ended Comments

Open-ended comments included a variety of themes including concerns about legality, interest in education materials, concerns about possible negative effects from use and method of use. Regarding concerns related to legality, participants provided additional information on what indications are permitted in their state such as chronic pain as well as concerns about discussing it in those states where cannabis is still illegal. Participants appeared to be very open to availability and use of educational resources related to cannabis and CBD, including

which indications there may be data supporting possible use (e.g., pain, behavioral health). Comments related to possible negative impact of use included side effects, transplant eligibility, possible impact on development of life management skills, and decreased adherence to medically directed CF treatments. Additionally, it was noted that harm reduction strategies is being applied by participants in care or suggested as a possible approach. Participants' open ended comments appeared to be more in support of edible or topical method of use versus inhaled, which is not unexpected as well as noting that inhaled method of use may be attributed to cost and perceived effectiveness.

Discussion

This is the first survey study to describe care team use assessment, documentation and education about recreational and medical cannabis use in persons with CF. A recent study surveyed people with CF in New Jersey and Pennsylvania about marijuana for medical use.¹¹ Sixteen percent of survey respondents had used marijuana and provided reasons for and method of use. Previous literature specific to cannabis in CF has comprised of lung damage from inhalation and substance use disorder. These include a case report on lung damage from cannabis inhalation,¹² and three studies assessing risky behaviors including cannabis use in youth^{13,14} and adults¹⁵ with CF. A more recent study determined that airway epithelial exposure to THC results in decreased expression and function of CFTR, therefore disrupting fluid homeostasis in the lung.¹⁶

There is a paucity of data regarding potential uses and effects of cannabis or CBD containing products specific to CF disease. In 2002, Ester Fride, an Israeli scientist hypothesized that lipid imbalances of high arachidonic acid and low docosahexaenoic acid (DHA) with CFTR dysfunction may lead to low endocannabinoid levels.¹⁷ She suggested that stimulating the system with phytocannabinoids found in cannabis, may decrease some symptoms associated with CF, such as nausea, vomiting, diarrhea, inflammation and pain. In

2005, Fride published study findings of the peripheral effects of CBD and synthetic CBD compounds, concluding that CBD should be studied in CF for its anti-inflammatory and anti-diarrhea effects.¹⁸ The CF Therapeutics Development Research Network recently concluded a study with lenabasum, a synthetic selective cannabinoid receptor type 2 (CB2) agonist.¹⁹ Activation of CB2 triggers processes to diminish inflammatory mediators. Lenabasum failed to meet primary endpoint of reduction in pulmonary exacerbations, however sub-analyses have not yet been reported.

Surveys regarding healthcare providers' views on medical cannabis have been conducted in other patient populations. Family physicians in Colorado and interdisciplinary health care providers in Washington State reported the need for further education and training about medical cannabis, specifically in medical school, residency training and through continuing education (CME).^{20,21} Both surveys found that more providers received their information about cannabis from news media or colleagues than from CME and that formal training should be a requirement before recommending medical cannabis to patients. A survey of emergency department physicians from across the US found that 31% of respondents felt knowledgeable about the endocannabinoid system and 68% believed that cannabis had medical value.²² Physicians who had personally used cannabis either for medical or recreational purposes were more likely to recommend use to patients. A national survey conducted in 2016 of US medical school deans found that only 24% felt that their graduates were moderately, very or extremely prepared to answer patient questions about medical marijuana.²³ An associated curriculum content search found that less than 10% of US medical schools include medical marijuana education. Our survey findings align with research in other populations, in that they demonstrate a need for increased cannabis education among health care professionals. This survey is unique with the included assessments of CBD knowledge. While the majority of CF care team members felt moderately to extremely prepared to answer questions about cannabis, the opposite was true of CBD, where the majority were slightly or not prepared. Participants felt

less knowledgeable about the differences of THC and CBD components and the majority never discussed these cannabinoid components with patients. The perceived lack of CBD knowledge was supported in the participant response related to advocated indications. For appetite, half of participants reported they would support the use of CBD, however CBD is associated with decreased appetite.²⁴ Interestingly, 20% reported they would support CBD for inflammation, and this may be one of the most desirable benefits of CBD.²⁵ A third of the survey participants were unsure what indications for CBD that they would support. Due to variability in state laws regarding cannabis and CBD, we expected differences in views and knowledge about these controversial substances. Many participants noted at least one reason not to support cannabis, with exclusion from transplant as most often cited concern. There are multiple different reasons participants were not in support, including legal status, addiction and brain development concerns. Along with those concerns was the request for education from all but a few participants. The objective of this survey study was to better understand how CF care teams are communicating with patients and families about cannabis and CBD and whether care teams are documenting use. There were differences in how often and where medical cannabis and recreational cannabis were documented in the medical record, with slightly less documentation of recreational use. Also interesting were the views on who in the interprofessional care team should be assessing use, with patients, with physician, social worker and nurse as the most selected. Ideally, CF centers should consider developing a standardized care team workflow with delineation of who assesses cannabis or CBD use and be equipped to engage in knowledgeable conversations with patients and have the ability to provide resources. Screening for potential adverse effects and drug interactions with these products is important.^{26,27} A limitation to our study is that the survey was sent via multiple listservs within the CF community. It is difficult to know how representative our participants are and whether our response rate is significant. An error in design was the survey skip logic only sent the cannabis prescribing practice questions to MDs and did not include midlevel practitioners, who are able to prescribe

in many states where medical cannabis is legal.²⁸ Despite these limitations, we were able to record valuable responses and opinions regarding cannabis and CBD in CF from multiple types of care providers.

Based on participant survey and open ended responses, there is interest in educational tools for care teams regarding approaches to use assessment, potential indications for which people with CF use cannabis or CBD, safety items including drug-drug interactions and adverse effects, suggested appropriate monitoring, and possible risks and benefits of documenting discussion about and reported use in the electronic medical record (EMR). To provide more robust and valuable education, further research in several of these areas would be beneficial, particularly around the implications of use in clinical outcomes and processes, such as evaluation for lung transplant.

Another potential area for future research would be examining clinician practices for drug-drug interaction screening and monitoring for adverse effects, such as psychiatric symptoms or cannabis hyperemesis syndrome. Understanding baseline patterns for these practices, and also the impact of future education on these practices, may be useful in determining the value or lack thereof of a specific educational intervention for care teams. As more states continue to permit increased access to these products, it will be crucial for CF care teams to feel prepared to answer patient questions regarding its impact on their overall health.

Conclusion

The CF care community would likely benefit from and are interested in educational materials regarding cannabis and CBD that specifically consider CF. Development of and dissemination of evidence-based and peer-reviewed educational materials should be considered as part of future CF care team initiatives. Availability of such education material may help facilitate the CF care team members to include cannabis and CBD into care discussions. CF Care teams should also consider developing workflows for assessment and documentation related to cannabis and CBD use to optimize consistency.

References

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