



Cannabis Use among Persons with Dementia and Their Caregivers: Lighting up an Emerging Issue for Clinical Gerontologists

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ABSTRACT

Objectives: Our goal is to illuminate cannabis use among persons with dementia (PwD) and their informal caregivers relative to the use of evidence-based as well as other complementary and alternative care practices.

Methods: We analyzed focus group (FG) narratives provided by 26 caregivers of PwD and identified five themes concerning the provision of cannabis to PwD and caregivers' self-use.

Results: Three of the 26 caregivers provided PwD cannabis and also used themselves, another 3 of the 26 used themselves only, and all but two of the remaining FG participants indicated they would consider providing cannabis to PwD or using for themselves. These caregivers expressed a desire to obtain more empirically-based information about cannabis and to discuss options with their clinical care providers.

Conclusions: A small but significant proportion of caregivers are providing cannabis to PwD as a possible treatment for agitation, sleep disturbances and other problematic secondary symptoms and using for themselves as way to relieve stress. Many other caregivers may start using cannabis upon receiving information and guidance from a credible source.

Clinical Implications: Notwithstanding the need for more research, clinical gerontologists and other dementia care specialists are being looked upon to provide information and guidance about the benefits and harms of cannabis use among PwD and their caregivers.

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Introduction

While researchers continue to search for a biomedical cure for Alzheimer's disease and related dementias, a number of pharmaceutical and non-pharmaceutical interventions have proven to slow disease progression and positively impact behavioral and psychological symptoms (Cummings, Morstorf, Zhong, & Cummings, 2014; Fazio, Pace, Maslow, Zimmerman, & Kallmyer, 2018; Livingston et al., 2017; Scales, Zimmerman, & Miller, 2018). Nevertheless, despite extensive public education and provider training efforts, most persons with dementia (PwD) do not access specialty-trained clinicians or use evidence-based programs and services (Noonan, Wilson, & Mercer, 2012).

As cognitive decline progresses and symptoms worsen, PwD move from being vulnerable to becoming entirely dependent on someone else for daily care. As an "unexpected career" that occurs without

planning or training, informal caregiving may expand an individual's purpose-in-life but it can also be devastating to mental and physical health due to the additional burdens and stress associated with caring for PwD (Karg, Graessel, Randzio, & Pendergrass, 2018). Chi et al. (2019) estimated that 22.3% of informal caregivers of PwD reported emotional difficulty, compared to 9.5% of informal caregivers of older adults without dementia. In addition, the proportion of informal caregivers reporting physical difficulty was twice as high for those assisting PwD (12.1%) than informal caregivers of older adults without dementia (5.9%). Although clinicians can recommend a number of evidence-based practices to reduce burden and improve overall health, most caregivers do not access or maintain participation in such programs and services (Gitlin, Marx, Stanley, & Hodgson, 2015).

When the dementia caregiving dyad (i.e., the person with dementia and the primary caregiver)

cannot access evidence-based practices or find such treatments may become less effective as cognitive decline advances and symptoms worsen for both the PwD and themselves, primary caregivers often seek out complementary and alternative forms of care on behalf of the PwD or for themselves. For example, even though such approaches have not been established as evidence-based, up to 40% of caregivers provide herbals, supplements and vitamins to PwD or use themselves as a complementary or alternative form of care (Rospenda, Minich, Milner, & Richman, 2010).

The emerging role of cannabis

Based on survey data collected from older adults in Illinois and Colorado (Arora, Qualls, Bobitt, Milavetz, & Kaskie, 2019; Bobitt et al., 2019; Lum et al., 2019), cannabis has emerged as another form of complementary or alternative care for PwD as well as their caregivers. In Illinois, among older adults who participated in the state's Medical Cannabis Pilot Program, Bobitt et al. (2019) identified thirty people who reported being the caregivers of persons diagnosed with Alzheimer's disease or a related dementia. Based on survey responses provided by their caregivers, they determined the majority of PwD (83%) were provided cannabis for emotional problems (agitation, anxiety or depression), half (50%) of PwD were provided cannabis for sleep disturbances, and a third (33%) received cannabis to treat pain. The majority of caregiver respondents reported PwD experienced a range of positive outcomes including improved affect, sleep and over-all quality of life. Only one caregiver identified a negative outcome of providing cannabis, reporting that it made memory functioning worse for the recipient.

In Colorado, survey data was collected from 274 adults aged 60 years and older (Arora et al., 2019; Lum et al., 2019). When looking at all of the survey respondents, Arora and her colleagues found that persons who used cannabis were more likely to identify themselves as primary caregivers compared to survey respondents who did not use cannabis. Among the 80 survey respondents who identified themselves as caregivers, regular cannabis users were more likely to report positive outcomes such

as improved sleep and quality of life compared to caregivers who did not use cannabis.

While these point-in-time, convenience samples did not generate reliable incidence or prevalence rates, we suspect cannabis use among PwD and their informal caregivers is going to increase substantially in the next decade as more states extend legalized medical cannabis to persons diagnosed with Alzheimer's or a related dementia (Kaskie, Ayyagari, Milavetz, Shane, & Arora, 2017). Cannabis use also is likely to increase among caregivers as more states move toward legalizing the "recreational" use of cannabis. Thirty-three states currently provide legal access to cannabis and, based on limited evidence, fourteen of these have included Alzheimer's disease and other dementias as qualifying conditions for medical cannabis program participation. Yet, the most recent NIH Forum on Alzheimer's disease as well as the 2020 National Institute on Aging Caregiving Summit did not present any studies about what occurs when PwD are given cannabis, and there are few other researchers who have considered this startling trend.

There is a lack of information about cannabis use among dementia caregiving dyads and what researchers have discovered about frequency, motives, and methods of cannabis use. It certainly would be important to learn if cannabis use by PwD mitigates agitation and aggressive behaviors, and whether this immediate outcome reduces caregiver burden. It also is worth considering if cannabis use by caregivers themselves corresponds with a sustained reduction in self-reported burden and a reduction in residential placement of the PwD. Meanwhile, clinical gerontologists and other dementia care specialists have little empirically based information to reference when responding to caregivers who ask about the benefits or harms that may occur when PwD are provided cannabis or when they use for themselves.

Research objectives

Our goal was to learn more about cannabis use among PwD and their primary caregivers. We relied on information obtained from focus groups (FGs) conducted among 26 primary caregivers of persons reliably diagnosed with dementia. We first discussed programs and services currently used by

caregiving dyads and then identified prominent themes concerning cannabis use as a complementary or alternative form of care. This study offers an original in-depth look into the use of cannabis among dementia caregiving dyads.

Methods

Between June and August 2019, we conducted six FGs with 26 persons who provided informal care to persons diagnosed with dementia of the Alzheimer's type. Participants were recruited from the population of informal caregivers of patients currently enrolled in the USC-Rancho California Alzheimer's Disease Center (CADC), and who provided care to someone who was evaluated within the past three years (2016-present) by the clinic's multidisciplinary team. A total of 300 potential FG participants initially were invited via a letter sent by U.S. mail. The letter included information regarding the time commitment (1.5 hrs.), location and the offer of compensation with a gift card valued at 50.00. USD These invitations were followed by phone calls over the next two weeks. Given resources and time constraints, we offered interested participants one of six times to attend a FG scheduled over an eight-week period and limited any particular group to a total of eight participants. Pseudonyms were used to protect the anonymity of the participants. The project was approved by the

Institutional Review Board of Rancho Research Institute which oversees the USC-Rancho CADC.

Sample

Age of the 26 focus group participants ranged from 30 to 89, with a mean age of 57. Group participants were mostly female (73.1%) and reflected a range in terms of ethnicity, education, marital status, income, and self-reported health. Most (73.0%) have been providing care for someone with dementia in the moderate to severe clinical stages for more than two years and spent more than four hours per day providing care (53.8%). Some of the caregivers identified themselves as children of the PwD while most others revealed they were the spouse of the PwD. Caregivers routinely observed affective, behavioral, and cognitive problems in providing care to PwD, and emotional strain was the most common self-reported challenge in terms of providing care to PwD, followed by sleep problems (see Table 1).

Data collection procedures

Upon arriving to participate in the FG, caregivers answered 40 questions providing background information about the care recipient as well as themselves. The questions also asked about the different type of evidence-based as well as complementary and alternative care practices provided to the PwD as well as being used by the caregiver. Our

Table 1. Sample characteristics.

Caregiver Characteristics (N = 26)		Caregiving Dyad (N = 26)	
Age (mean (range))	57 (30–89)	Length of Caregiving Role	
Gender (n (%))		More than Two Years	17 (73.0)
Male	7 (26.9)	Less than Two Years	7 (27.0)
Female	19 (73.1)	Hours Per Day Spent Caregiving	
Ethnicity		More than Four	14 (53.8)
Hispanic	12 (34.6)	Less than Four	12 (46.2)
Non-Hispanic	14 (65.4)	Stage of Dementia	
Education level		Moderate to Severe	19 (73.0)
College degree and above	18 (69.2)	Very Mild to Mild	7 (27.0)
Below college degree	8 (30.8)	Observed Symptoms	
Marital Status		Affective	18 (69.2)
Married/have a partner	18 (69.2)	Behavioral	9 (34.6)
Not married/single	8 (30.8)	Cognition	21 (80.7)
Financial status		Dressing	13 (50.0)
Financially comfortable	15 (57.6)	Eating	12 (46.2)
Less than comfortable	11 (42.3)	Diagnosed Co-Morbidities	
General QOL		High Blood Pressure	8 (30.7)
Poor	1 (3.8)	Diabetes	5 (19.2)
Fair	12 (46.1)	Primary Caregiving Challenges	
Good	9 (34.6)	Emotional	16 (61.5)
Very Good	3 (11.5)	Relationship	14 (53.8)
Excellent	1 (3.8)	Sleep	9 (34.6)

survey questions also asked about any other practices the caregiver applied to the PwD or themselves. These included exercise, socializing, alcohol and cannabis use. If a caregiver endorsed any of these options, a follow-up question asked the respondent to evaluate the outcomes in terms of helpfulness or harm.

Upon answering the survey questions, the informal caregivers then participated in a 60 to 90-minute FG that addressed the different types of care provided to the PwD as well as being used by the caregiver. The FG facilitator posed the following questions and allowed for an average of 10–15 minutes of discussion for each: (a) In regard to the person you care for, what has your doctor (or other health care provider) recommended? (b) Are you doing anything else to help the person you care for? (c) What are your thoughts about providing cannabis to the person you provide care for? (d) In terms of taking care of yourself, has your doctor recommended anything for you like prescription medication or otherwise? (e) Are you doing anything else to care for yourself? and (f) What are your thoughts about using cannabis as a way to take care of yourself? Each FG session was audiotaped, transcribed, and reviewed for reliability before initiating the analysis.

Analysis

We employed both a deductive and inductive thematic approach in conducting the FG analyses (Braun & Clarke, 2006). We first developed a code book using the seven

interview questions as a guide, and using an inductive approach we allowed for new codes to derive from the data. Three researchers independently coded a subset of two transcripts looking for emerging ideas. We then finalized six codes and tested our coding system on another subset of two transcripts to make sure we were applying the codes consistently and to make any needed adjustments to coding definitions. To increase reliability, three researchers reconciled all coding disagreements prior to finalizing the codebook. One researcher used the final code book to independently code all six transcripts in QSR NVivo software. We conducted a thematic analysis by analyzing each code for frequently used words and phrases using NVivo's Word Tree and Word Frequency functions. Then, we expanded on the text

and phrases identified and analyzed the comments within each code. After performing the analysis, we designated major themes. To be categorized as "major," a theme had to appear in all six of the groups, had to appear frequently enough within a group (discussed by two persons or more) to depict substantial interest among participants, and needed to constitute at least ten percent of all codes assigned to the transcripts. Alternatively, if a code only appeared in three of the six focus groups, was mentioned by only one individual in a FG, or constituted less than ten percent of all coded items, then it was not qualified as a major theme.

Results

The caregivers who participated in the FGs reported that clinicians prescribed medications as the most common approach to treating PwD but it should be noted that not all individuals with presenting symptoms received a prescription (see Table 2). In particular, 9 of the 26 PwD were prescribed a medication for cognitive decline; 13 of the 18 PwD who presented with agitation, anxiety or depression received a prescription; prescriptions were filled by 6 of the 9 PwD who presented behavioral problems and 9 of 12 PwD with sleep problems. A non-pharmaceutical practice was recommended for only one of the persons with dementia (i.e., physical therapy). Among the 16 caregivers who reported experiencing affective problems, only 4 were prescribed medications, 2 of 8 caregivers with pain received a prescription, and 2 of 9 with sleep problems were prescribed medications. A small number of caregivers indicated their providers recommended they participate in caregiver training programs; increase exercise, leisure and social pursuits; or attend caregiver support groups and use respite programs.

Caregivers provided a range of complementary and alternative care to PwD. The most common involved the provision of over-the-counter products including herbals, supplements, and vitamins ($N = 14$). Five caregivers enrolled the care recipient in a cognitive training program and four engaged PwD in yoga or exercise therapy. Three of the twenty-six caregivers provided cannabis to their care recipient; one reported cannabis was "very helpful", another reported it was "somewhat helpful" and the third indicated it

Table 2. Approaches to care (type by recipient).

Clinician Prescribed or Recommended				Self-Administered		
Care Recipient (PwD)				Care Recipient (PwD)		
Medication (total indicated, using, benefitting*)				Ingestible (total using, benefitting)		
Affect	18	13	9	Alcohol	1	0
Behavior	9	6	5	Cannabis	3	2
Cognition	21	9	4	OTC Supplements	14	5
Sleeping	12	9	7	Behavioral		
Non-Medication				Cog Training		
Physical Therapy		1	0	Exercise-Yoga	4	2
Caregiver				Support Groups		
Medication (total indicated, using, benefitting*)				Caregiver		
Affect	16	4	4	Ingestible		
Pain	8	2	2	Alcohol	3	3
Sleeping	9	2	0	Cannabis	6	5
Non-Medication				OTC Supplements		
Education		1	0	Behavioral	9	7
Support Groups		2	1	Education	4	3
Exercise		3	2	Support Groups	15	14
				Exercise		

* Helps a lot or somewhat

helped “a little.” Caregivers also used a range of complementary and alternative approaches themselves. Fifteen participated in yoga or exercise classes; 9 of the 26 took over the counter products including herbs, nutritional supplements and vitamins; 9 of 26 participated in a caregiver training program and four regularly attended caregiver support groups. Six of the twenty-six caregivers used cannabis in the past year and reported that it was “very helpful” or “somewhat helpful”.

Focus group themes

Upon reviewing the FG transcripts, we identified five major themes including: 1) a lack of provider guidance or recommendations for the care of PwD; 2) clinicians overlooked caregiver needs; 3) caregivers provided PwD a variety of complementary and alternative care including cannabis; 4) caregivers used a variety of coping methods for themselves including cannabis; and 5) caregivers expressed interest in learning more about providing cannabis to PwD or using for themselves. We now highlight each theme with a sample of supporting quotes from the FG discussions.

Lack of provider guidance and recommendations

The FG conversations revealed how providers focused on well-established pharmaceutical approaches such as acetylcholinesterase inhibitors

(usually donepezil) and/or prescription medications for anxiety, depression and/or sleep problems. Three caregivers mentioned how their clinicians suggested they look for extra help in the form of additional home care, adult daycare or long-term care. None of the FG participants indicated their providers discussed complementary and alternative approaches including cannabis.

“I’ve had doctors recommend medicine. XX and XX I eventually said I think we’re gonna take him off this one cause this one is running a four hundred dollar a month copay and I’m not sure it’s doing anything.” FG2 CG1

“They did start on the medications . . . But I had heard about the side effects this and that. I said we’re having enough trouble just the way he is without having him take this medication and then also have the side effects in addition to the Alzheimer’s so we turned XX down, no medications at all. Dealing with Alzheimer’s was enough, to have to deal with side effects.” FG5 CG1

Caregivers are often overlooked

When meeting with clinicians, caregivers discussed how they were often overlooked because the “patient” is the PwD and the examination time was often limited such that providers did not directly engage the caregiver and evaluate his or her needs. A few providers discussed options for getting formal support such as in-home care. None of the providers discussed using cannabis to relieve caregiver stress or otherwise.

“What really intrigued me about this survey you’re doing and the questionnaire that we’re filling out is hopefully you’ll get a better impression of how to deal with the ‘other’ patient . . . I think my wife gets a lot of focus from a lot of different doctors. No one ever says so how are you doing? And how are you reacting? How is this making you feel?” FG1 CG2

“Yeah my doctor knows what I do and he hasn’t given me anything . . . I think he probably asked me once are you getting enough sleep? And I am, so that’s fine.” FG5 CG2

Caregivers employ a variety of care practices for the recipient including cannabis

With little direction from clinicians, caregivers are providing a variety of unproven complementary and alternative practices to the care recipient based on trial and error, their own research, or advice from family and support group members. The type of practices ranged from over the counter ingestible products like herbals, supplements and vitamins to participating in exercise and yoga programs. A few caregivers talked about making home modifications (i.e. child-proof locks, leaving notes). Three caregivers disclosed they provided cannabis to the care recipients and all but two of the twenty FG participants who were not providing cannabis to the PwD or using themselves revealed they would consider doing so if there was a need or their provided recommended doing so.

“We tried vitamins and herbal stuff that friends and family recommended for anxiousness.” FG6 CG5

“So I finally realized she keeps forgetting what I’m telling her so I’ll just put a little note here on the wall, tape it to the wall right next to the thermostat and that worked . . . And then I . . . put on the window too, so little things like that . . . I’ll leave a note in the kitchen where she’ll find it so she doesn’t have to remember that I told her something in the morning.” FG5 CG2

“But overall it (cannabis) helped a lot. We added it to the melatonin because we found that the melatonin and the trazadone on their own weren’t working . . . It has created a sort of ability to sleep . . . Recently we added gummies with THC. to see how it improves her appetite because that’s our struggle with her right now.” FG2 CG3

“I tried it (cannabis) for a while without the THC. I was buying it from a legitimate place – they, you

know, said it deals with anxiety and stuff like that . . . it’s the greatest stuff . . . I don’t think it can hurt anyway” FG4 CG3

“Yeah, it works enough to where it’s something that we want to continue doing. We’re still playing around with the dosage a little bit we’ve even done like a THC lemonade and that’s actually helped a lot, it’s just a little harder to come by because you have to find someone who knows how to make them.” FG4 CG3

“It’s supposed to calm them down and reduce like anxiety. We kind of gave it to my Dad a little bit on and off because we we’re trying other things and they weren’t helping but I don’t necessarily know that it did much for him. Yeah so plus it’s super expensive.” FG6 CG1

“I said I would consider (giving PwD cannabis), I would probably have to check if there’s any interaction with her medication. Cause she’s taking a lot (of prescription medications).” FG2 CG5

Caregivers are using a variety of coping methods including cannabis

In response to the question asking caregivers what they do to take care of themselves, the discussion often turned to stress and coping techniques and we found caregivers rely on a variety of methods. These range from participating in exercise and yoga classes to taking herbals, supplements and vitamins. Some caregivers indicated they drink alcohol in moderation and others use cannabis. Nearly all of these approaches were considered beneficial.

“I exercise 3 days, I have a trainer . . . She comes and beats me up in the morning’s at 7 o’clock every Monday, Wednesday and Friday.” FG3 CG1

“Right, I tried to pick up healthy lifestyle changes for myself to get through this . . . Running, my thing is running so every day. I go out there and run.” FG1 CG2

“ . . . see how to take care of myself so I’m taking a vitamin and supplements and trying to eat healthy and to be the best as I can but it’s still not enough . . . I take a multivitamin, vitamin D, vitamin B, glucosamine chondroitin, hyaluronic acid.” FG6 CG1

*“I drink almost every day but ya know one glass. Red, I just consider myself like French. *all laugh* . . . I work all day and when I go home then I go to my*

room first I get myself a big gulp of wine and then I can face the world.” FG2 CG5

“I might consider only because I’ve done some research and I have kids who are in their 20s and they tell me that the THC will help her rest and help keep her comfortable we’ve never tried it but because I don’t have any evidence you know to prove that but that’s what they say.” FG3 CG8

“I use cannabis every night. I have an edible that I take before I go to bed. It doesn’t work totally a hundred percent because I have a lot of trouble sleeping. I had a prescription. Now you don’t need a prescription, you just walk in and buy it . . . ” FG5 CG4

“I have permanent nerve damage and pain in my face and my hand and my pain management specialist recommended I try it (cannabis) and it helps me a lot at night . . . for sleep and so I think it’s really helpful.” FG1 CG1

“So I’ve only done the CBD but the CBD for myself I feel a little groggy in the morning so I think I just have my own correct dosage but I use it maybe once every 2 months I don’t use it very often just when I feel I really need it and I can’t relax at night.” FG2 CG3

“And there’s where I would turn – if you’re very comfortable in the support group I would say I would like to explore this (using cannabis) and if there’s anybody here who has – and would be willing to talk to me about it cause it would be really nice. If you go to a good, reputable place which most of them are, they’re very willing to help you and talk to you and ask you what you’re looking for.” FG5 CG2

Caregivers expressed interest in learning about cannabis from a clinician

Discussion about cannabis often came up naturally during the discussions regarding complementary and alternative care practices, and involved providing cannabis to the person being cared for as well as taking cannabis as a coping mechanism. For those individuals who currently do not provide cannabis to PwD or use for themselves, 18 of 20 indicated they were open to learning more or engaging with their clinicians in further conversation.

“That’s the only problem. My brothers and I have done a lot of research on it and the problem with CBD and THC is that there is no guideline to dosage.

There is no- if the patient weighs x amount of pounds this is how much you’re gonna give them. It’s a trial and error.” FG2 CG3

“I’ve never been opposed to smoking dope because I was a hippie at one time . . . I just would want to have somebody, a Doctor, try to tell me that that was the right thing to do. I don’t know who you go to and who is qualified to tell me that that’s something I could have my husband do, you know? Until I had somebody say, that I felt was qualified, to tell me that this was a good thing for him I might consider it.” FG4 CG1

“And the fact of the matter is that I don’t think there is a lot of research on it so we’re all kind of guessing and ya know I think when you go through enough frustration or have enough concern about your loved one you’re kind of desperate to try anything that might work unless you read a lot about how ya know there could be a lot of negative side effects and then you hopefully make an informed decision but with CBD with cannabis there’s just not a lot of research unfortunately.” FG1 CG2

“Before I started giving it to my wife I called down and spoke and said ‘ . . . before I go do something like this I’m just checking in with you and what was the experience down at xxx’. And their comment was basically that it’s not something we’re into – whatever so I said ‘fine I understand’. Not knowing anything about marijuana or the affects or whatever kind of just checking with what I thought would be the medical profession . . . they didn’t really have information.” FG2 CG2

“For me I was kind of brought that subject up with my mom but I honestly was scared to give her any even the low dosage of the high part I was just really scared for how she would react to it so I never gave it to her. I kind of mentioned it to her (doctor) when it came up but she kind of didn’t not approve but wasn’t for it, so but I wasn’t either so I wasn’t really like asking benefits or not so we ended up not trying it on her.” FG2 CG6

Discussion

The caregivers in our study affirmed how clinicians rely on prescription medications as the primary treatment for PwD (American Psychiatric Association, 2010). We also learned that not all PwD receive prescription medications when indicated and others quit

using prescribed medications because they become less effective as dementia progresses (Cheng & Zhang, 2020; Cheng et al., 2020). Clinicians seldom recommended non-pharmaceutical treatments for PwD or their caregivers, and they rarely discussed complementary and alternative approaches including cannabis. We also affirmed how clinicians often overlook the needs of caregivers.

Indeed, PwD and their primary caregivers appear to be left navigating disease progression largely on their own with little professional guidance. Within this context, our FG analyses affirmed how a substantial number have turned to complementary and alternative approaches that have not been established as evidence-based. Caregivers provide PwD herbals, supplements, and vitamins; enroll PwD in cognitive training and mindfulness programs; and make modifications to their home. They also take herbals, supplements, and vitamins themselves, and engage in other practices (like self-education and exercise). Interestingly (and perhaps unsurprisingly), they consistently report these approaches are helpful. Clinicians should consider increasing their engagement with caregivers when developing treatment and care approaches for the PwD or for the caregivers themselves, especially with the substantial self-directed use of complementary and alternative approaches, including cannabis.

We affirmed previous survey findings in Illinois and Colorado and have established that caregivers are providing cannabis to PwD and using themselves. While our sample size is small and not representative, their use appears to be slightly higher than what might be expected compared to the non-caregiving, older adult population (Han et al., 2017; Salas-Wright et al., 2017). Perhaps more important, the motivation for providing cannabis to PwD differs than what might be expected. While most older adults use medical cannabis to manage pain (Bobitt et al., 2019; Lum et al., 2019), the caregivers in this study reported providing cannabis to PwD as a way to manage emotional (e.g., agitation, anxiety) and sleep problems. Given how caregivers who provided cannabis to PwD also reported positive outcomes and considered cannabis as a safer alternative to alcohol, other illicit drugs, and prescription medications (Bobitt et al., 2019; Lau et al., 2015), clinicians should expect to

observe increasing cannabis use among PwD especially as other evidence-based approaches may become less effective as the disease progresses. Moreover, our results affirmed how caregivers may increase their own use of cannabis to reduce stress and address other detrimental outcomes that correspond with the increasing burdens associated with caring for PwD (Arora et al., 2019).

As such, clinicians should become more familiar with the varied types of cannabis use and the corresponding range of outcomes, both negative and positive, that have been identified among non-demented older adult samples (Choi, Dinitto, & Arndt, 2019; Croker et al., 2020; National Academies of Sciences, Engineering, and Medicine, 2017). For example, the National Academies cited a substantial amount of evidence that supported an association between cannabis use with worsening respiratory symptoms and frequent episodes of chronic bronchitis while Hudson and Hudson (2020) linked increasing cannabis use among older adults with mental status alterations and acute intoxication. Alternatively, Charernboon, Lerthattasilp and Supasitthumrong (2020) suggested nabilone (a cannabis derivative) may reduce agitation among PwD. Other researchers (Black & Joseph, 2014) have analyzed nationally representative surveys of cannabis use and found nearly 95% of older persons who used cannabis in the past year reported no emotional or functional problems and placed no limitations on their own use.

It is indeed concerning how little clinicians seem to know about the benefits and harms of cannabis, proper dosing, and potential interactions with other prescribed and non-prescribed medications (Baumbusch & Sloan Yip, 2020) especially as researchers have observed how clinicians who possess such little knowledge have high levels of discomfort in discussing and recommending medical cannabis to patients (Carlini, Garrett, & Carter, 2017; Philpot, Ebbert, & Hurt, 2019; Szyliowicz & Hilsenrath, 2020). Relative to the considerable amount of uncertainty that caregivers expressed about knowing the benefits and harms of cannabis use and their preference to seek out guidance from professionals, clinicians should become more adept with offering information and facilitating discussion with PwD and their caregivers.

While we are not suggesting that clinicians need to recommend cannabis as a complementary or

alternative form of treatment or refer patients to state cannabis programs, clinicians should embrace the notion that dementia caregiving dyads have a strong preference to discuss cannabis with professional providers with whom they have ongoing relationships, know their medical histories, and are the most appropriate to provide a referral to a state medical cannabis program (Han et al., 2017). If anything, when conducting routine evaluations with dementia caregiving dyads, clinicians should incorporate questions about cannabis use to the same extent they ask about the use of prescription medications and other substances (herbals, supplements, alcohol and illegal recreational drugs). If clinicians do not collect and discuss such essential information, PwD and their caregivers who are using cannabis may experience negative outcomes such as drug interactions and medical complications that could otherwise have been prevented.

Limitations and Future Directions

We recognize a small sample recruited from one clinical site in a specific geographic area may not reflect the larger population of PwD and their caregivers. This research study also fell short in answering critical questions such as: Does cannabis work as a suitable or detrimental complement to prescribed medications? Does cannabis control or exacerbate hallucinations among PwD? How much cannabis should be provided to PwD? Does using cannabis help caregivers continue to keep PwD at home? Does cannabis use among caregivers contribute to problems with using other substances such as alcohol or opioids?

We are eager to follow this initial work with a more comprehensive study of a larger, representative sample of caregiving dyads to further illuminate the use of cannabis relative to evidence-based care and other care approaches. We aspire to determine how decisions to use cannabis are shaped variably by outcomes associated with evidence-based care, dyad characteristics such as race and ethnicity, provider approaches, and contextual conditions such as access to a medical cannabis dispensary. We look to associate specific kinds of cannabis with both desirable (reduced agitation) and undesirable (increased falls) outcomes. Meanwhile, clinicians should recognize the use of cannabis among PwD and their caregivers may increase whether they offer information and guidance or not.

Implications for clinicians

- Clinicians need to acquire more knowledge about frequency, motives and methods of cannabis use among older adults in general, and among PwD and their caregivers in particular.
- Clinicians may wish to become familiar with the range of undesirable and beneficial outcomes experienced by persons who use cannabis.
- Clinicians may wish to consider including questions about cannabis use as part of formal evaluations of dementia and being open to conversations with PwDs and their caregivers about the potential harms and benefits cannabis use.
- Clinicians need to become familiar with their clinic or health system's positions on discussing cannabis with patients and with referral mechanisms to state medical cannabis programs.
- Clinicians should consider calling upon their professional provider organizations to offer cannabis education and training, and developing standards for incorporating cannabis into patient care.

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