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Attitudes, beliefs, and changing trends of cannabidiol (CBD) oil use among caregivers of individuals with Alzheimer's disease

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ABSTRACT

Objectives: With the increasing popularity of CBD-based products, especially CBD oil, it is increasingly important to understand what motivates caregivers of individuals with Alzheimer's disease (AD) to use CBD oil as part of treatment. The purpose of this study was to identify the attitudes and beliefs of caregivers of individuals with AD toward CBD oil in Poland, to identify factors that might be associated with the decision to use CBD oil among caregivers, and to explore whether such a decision was discussed with a healthcare professional.

Method: A cross-sectional online survey was conducted in Poland. Participation in the study was entirely voluntary and completely anonymous. Caregivers (n = 73) were asked about their practices and attitudes regarding CBD oil.

Results: The most common source of knowledge about CBD oil was an online support group for caregivers. The vast majority of caregivers found CBD to be effective in managing behavioral symptoms of AD and believed that healthcare professionals should offer CBD oil as a part of treatment. However, only 63 % (n = 46) reported consulting with their physician about using CBD oil. The study also demonstrated that some caregivers thought that CBD oil use was illegal in Poland and that their care-recipient may develop a dependence and withdrawal symptoms if they stopped using it.

Conclusions: The results of the study highlight the positive and negative perceptions among caregivers of people with AD. The study also emphasizes the importance of enhancing communication between caregivers and healthcare professionals to discuss the use of CBD oil in the treatment of individuals with AD.

1. Introduction

Alzheimer's disease (AD) is a neurodegenerative disease and the most common form of dementia.[1,2] It is a progressive disease characterized by symptoms such as an impairment of memory, difficulty solving problems, and a gradual loss of communication abilities.[3] These symptoms worsen as the disease progresses and significantly impair a patient's quality of life.[4,5] It is estimated that there are 44.4 million individuals worldwide living with AD or a related form of dementia and this number is expected to increase to 152 million by 2050.[6] Because the prevalence of AD increases with age, the number of individuals affected by this disease will grow as the population continues to age and longevity rates increase. It is, therefore, highly likely that AD will affect a significant number of older adults, and consequently, pose a burden to their health and to families around the world.

The physical and emotional demands associated with attending to the needs of an individual with AD can have adverse effects on caregivers. Studies have demonstrated that caring for a person with AD is more stressful than caring for a person with a physical disability[7] and has been associated with increased levels of anxiety, stress, and depression, as well as a diminished immune response.[8] Among the factors causing the most caregiver distress are the behavioral and psychological symptoms (BPS) of AD that include agitation, wandering, sleep disruption, disinhibition, irritability, and outbursts of aggressive behavior.[9,10] These BPS are common. In fact, it is estimated that they can affect up to 90 % of individuals diagnosed with AD at some time during the progression of the disease.[11,12]

The BPS pose unique challenges for caregivers because they can be not only emotionally and physically depleting, but they may also accelerate the care recipient's cognitive decline.[13] Of equal concern is that these symptoms may also contribute to increased healthcare utilization costs and earlier nursing home placement of the patient.[14,15] With

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the growing costs of long-term care, the untreated BPS of AD may increase overall costs of care for both caregivers and health systems.

The management of the BPS depends on the symptom, its severity, the distress experienced by the patient, and the safety concerns of any caregivers. Often it includes treatment with neuroleptics and other antipsychotics. However, the therapeutic options and their efficacy are limited. Moreover, long term usage of psychotropic medications among individuals with AD has been associated with increased fall risk and mortality risk.[16–18] Taking into account that there is no effective treatment available and that the current treatment options are associated with significant risks for patients, caregivers have been prompted to explore alternative options for coping with the BPS.

Due to its use for certain health conditions, including AD, medical cannabis has received much attention in the past decade. While its adoption remains controversial, research clearly demonstrates that public opinion toward a medical cannabis policy has been changing.[19–21] The medical use of cannabis has been gaining increased social acceptance, which is also reflected in an increasing number of countries around the world that have legalized the use of medical cannabis.[22]

While medical cannabis has been more widely accepted in the USA, Canada, and many parts of Europe, including the Netherlands, Germany, and the Czech Republic, in Poland, medical cannabis was only officially legalized for use as recently as November 2017. The possession and practice of recreational cannabis remains illegal. In terms of medical use, Polish law allows only the use of certain cannabis-derived pharmaceuticals such as Sativex, which is available only by prescription from a physician who must use a special electronic prescription form. Other drugs derived from cannabis can be imported by a patient only upon receiving a formal approval from the Ministry of Health.[23] The country has been importing medical cannabis from Germany and despite requiring formal approval, these products are not covered by health insurance.[24]

Although limited, there is scientific evidence indicating medical cannabis' efficacy in relieving BPS among individuals with AD.[25] However, the limited number of suppliers combined with the high costs of certain drugs makes it challenging for many patients, including those with AD, to be able to access medical cannabis. Currently, there is an increasing public pressure to open up the market and allow for the domestic production of medical cannabis.[26]

Due to a number of restrictions and the increasing costs of medical cannabis, cannabidiol (CBD)-based treatments have grown in popularity and are generating considerable interest from scholars and the general public. Cannabidiol (CBD) is the second most abundant cannabinoid found in the *Cannabis sativa* plant after tetrahydrocannabinol (THC), that has therapeutic potential including anti-inflammatory and antioxidant effects.[27] Contrary to THC, CBD is not a psychoactive substance nor does it trigger the "high" commonly associated with THC.[28,29] Thus, CBD products have been advertised as a treatment for many diseases or conditions (e.g. anxiety, epilepsy, or pain management).[30] Some studies suggest that CBD may be beneficial in managing BPS of AD patients.[31] However, despite the growing demand for its adoption as a form of care, these studies suffer from certain methodological flaws including their small sample sizes and a lack of well-controlled trials.[32] Therefore, the results should be interpreted with caution.

Though data regarding the effectiveness of CBD products in treating the symptoms of AD is scarce, the use of CBD products, especially CBD oil, is becoming more popular. Slovakia is currently the only European country in which CBD is illegal. Under the European Union, CBD products with less than 0.2 % THC are legal in many countries, including Poland, and can be purchased online or over the counter as long as they do not exceed 0.2 % THC. CBD products in Poland are classified as a dietary supplement, which means that caregivers are not required to consult with their physicians or obtain a prescription for these products.

Little is known about the attitudes and practices regarding CBD oil, especially among the caregivers of individuals with AD. The purpose of this study was to estimate the prevalence of its usage and the attitudes toward CBD oil among caregivers' of individuals with AD living in Poland. In 2019 the number of individuals aged 65 and older in Poland constituted of 18.8 % of the total population and that percentage is projected to increase to 30 % by 2050.[33] With the current demographic trends and a growing number of individuals with AD in Poland, an increasing number of caregivers may start using CBD oil to treat disease-affected individuals. Moreover, as the population in Poland ages and an increasing number of individuals is being diagnosed with AD, it is becoming increasingly important to understand the factors that influence CBD oil usage and whether caregivers have discussed its usage with their healthcare providers. Addressing the issue of using CBD oil among caregivers of individuals with AD is of critical importance for a number of reasons. Caregivers may be using CBD oil either in conjunction with other recommended treatments or may be using CBD oil alone in the management of the BPS. Although the therapeutic effects of CBD are promising, it is still unknown how these products might interact with other drugs and what the long-term side effects are. It is possible that caregivers may be reluctant to consult with their primary healthcare professional about using CBD oil and experimenting with a dosage. Another reason why investigating the attitudes toward CBD oil among caregivers is important is the fact that in many countries CBD oil is a dietary supplement that also evokes certain safety concerns about the quality of product content. A lack of regulations and different manufacturing standards can affect the quality and strength of any plant[34] which may be utilized to make CBD products rendering them either ineffective or even potentially dangerous in some cases. It is, therefore, no surprise that some caregivers are reluctant to adopt this treatment option. To the best of our knowledge, no prior study has performed an investigation to understand caregivers' attitudes and adoption of CBD oil use. The results from this study may help researchers and practitioners gain a deeper understanding of what motivates caregivers to use CBD oil as well as learn more about the barriers caregivers face while discussing its usage with other healthcare professionals.

2. Methods

2.1. Participants and procedure

A cross-sectional online survey was conducted in Poland, in June 2020. Recruitment information was listed on two online support groups for caregivers and on social media (the authors posted an ad and targeted several Facebook pages related to caregivers). The invitation to take part in the study included a short description of the study, the name and address of the investigator, inclusion criteria, an estimated time commitment required for participation, and information that the study was completely anonymous. Interested individuals were invited to participate in the study by following a link to the online survey. Participation in the study was entirely voluntary. Eligibility criteria were that participants: 1) were adults aged 18 years or older; 2) had to be the primary caregiver of a care-recipient who had physician-diagnosed (by a neurologist or psychiatrist) AD for at least a year; and 3) were currently administering CBD oil to their care-recipients. No incentive or compensation was provided for participation. Overall, 73 CE caregivers participated in the study.

2.2. Measures

The demographic information obtained included age, gender, education, place of residence, relationship to the care recipient, and amount of time since the diagnosis. Participants were asked a series of questions regarding the frequency and dosage of the CBD oil used. Questions also addressed the reasons for their use of CBD oil, its effectiveness using a five-point Likert scale (not at all, somewhat, fairly, effective, completely effective), and any side effects of the CBD oil.

The questionnaire was designed by a psychologist and a physician on

the basis on previously published research on attitudes and beliefs toward cannabis.[35–39] Questions were pilot tested among a group of 10 caregivers for content and clarity and revised based on participants' feedback. Questions measuring the attitudes and beliefs toward CBD oil were: 1) Since you started using CBD oil, is your attitude toward it: more positive, the same, more negative; 2) Have you talked to your doctor about using CBD oil? (1- yes, 2- no); 3) Where do you get your information about CBD oil from? (respondents were asked to select all that apply from a list of options e.g. friends, family members, online support groups, etc.); 4) In the future, how likely do you think it will be that CBD oil will be used in managing or treating AD symptoms? (1 -very unlikely, 2- unlikely, 3- undecided, 4- likely, 5- very likely); 5) What is your opinion of the current legal status of CBD oil in Poland? (an open-ended question). A few statements used a five-point Likert scale that ranged from strongly disagree to strongly agree: 1) CBD oil is helpful in treating the symptoms of AD, 2) Healthcare professionals should be offering CBD oil to patients with AD to help manage difficult behaviors, 3) CBD oil use is becoming more socially acceptable, and 4) CBD oil has improved my care recipient's quality of life. Participants could also leave comments if they wanted to add information about their situation. The survey took an estimated 10 min to complete.

When planning the study, we took steps to decrease the chance of missing data. First, during the informed consent process, we included information about the importance of completing all the items in the survey. Secondly, the questionnaires were completed online. If the questionnaire was completed but there were some missing items, the system asked participants to fill out the missing questions.

2.3. Statistical analysis

Descriptive statistics (frequencies, percentages, means, and standard deviations) were used to describe caregivers' demographic information and attitudes. Answers to open-ended questions were analyzed for common themes. Data was analyzed using IBM Statistical Package for the Social Sciences (SPSS, Chicago, Illinois) version 23.

2.4. Ethics

Prior to data collection, ethics approval for data collection was provided by the Institutional Review Board of the University of [name removed]. The study was also conducted according to the criteria set by the World Medical Association Declaration of Helsinki.

3. Results

3.1. Caregivers' demographic information

Seventy-three caregivers of individuals with AD completed the survey. Descriptive statistics for the sample (e.g., age, education, duration of caregiving) are provided in Table 1. Participants were, on average, 51.18 years of age (SD = 10.7, range 32–70). The sample was largely female (95.9 %, n = 70). Educational attainment was relatively high: the majority of caregivers (76 %) had obtained a college degree. All participants were white native speakers of Polish, which reflects the composition of the geographical area.

The most common reasons caregivers offered for the use of CBD oil was to slow memory loss and manage certain symptoms of AD such as agitation, anxiety, and insomnia. Twenty-seven participants (37 %) disclosed that they had not discussed the CBD oil usage with their physician. The vast majority of caregivers reported positive effects of the CBD oil and said that CBD improved their care recipient's quality of life (84 %), although five caregivers reported that CBD turned out to be ineffective in managing AD symptoms. With respect to side effects, none of the caregivers reported any adverse effects of using the CBD oil. Almost 90 % (n = 66) of caregivers reported that since they had started using the CBD oil, their attitude toward it had become more positive.

Table 1
Social-demographic characteristics of the participants (n = 73).

Variable	CBD oil users (n = 73) *M (SD)*
Age (in years)	51.18 (10.7)
Gender, n (%)	
Male	3 (4.1)
Female	70 (95.9)
Education, n (%)	
Less than high school diploma	0 (0)
High-school graduate or equivalent	17 (23)
College degree and higher	56 (76)
Employment status, n (%)	
Full-time	14 (19)
Part-time	45 (61.6)
Unemployed	2 (2.7)
Retired	12 (16.4)
Duration of care (years)	3.53(1.98)
Living with the care-recipient, n (%)	
Yes	70 (95.9)
No	3 (4.1)

Abbreviations: M, means; SD, standard deviation.

When asked to specify the source of their knowledge about CBD oil, the most common response was an online support group for caregivers (62 %). Only 7 (10 %) out of 73 respondents were educated about CBD oil by a healthcare professional (e.g., a physician or a pharmacist). The remaining caregivers researched CBD oil on blogs or gained information from their friends or family members.

3.2. Caregivers' attitudes and beliefs regarding CBD oil

The second part of the survey measured caregivers' attitudes toward CBD oil. Table 2 summarizes caregivers' responses in regard to CBD's effectiveness in managing AD symptoms. Caregivers felt that CBD oil was helpful for treating the symptoms of the disease (M = 1.26, SD = 0.60). Of the sample of caregivers surveyed, the majority agreed that CBD oil use is becoming more socially acceptable.

Of the 73 respondents, 24 caregivers (33 %) chose to leave a comment at the end of the survey. The most common theme concerned being misunderstood or judged if they started a conversation about the use of CBD oil use with a physician. The second theme was caregivers' apprehension about the current legal status of CBD oil in Poland. Some of the caregivers expressed a desire that CBD not be sold as a dietary supplement (over the counter) but instead be classified as a medication and regulated by the government. A few caregivers (n = 7) pointed to the need for increasing the general population's awareness about CBD products because people often confuse it with medical cannabis.

4. Discussion

Coping with the challenging situations and BPS of AD remains a challenge for many caregivers. The current standards of care are based on controlling the symptoms and usually include antipsychotic

Table 2
Assessment of caregivers' attitudes towards CBD oil.

	Caregivers M (SD)
1. In the future, how likely do you think it is that CBD oil will be used in managing or treating AD symptoms	2.19 (0.74)
2. CBD oil use is becoming more socially acceptable	2.10 (0.89)
3. Healthcare professionals should be offering the CBD oil to patients with AD for managing difficult behaviors	1.84 (0.71)
4. CBD oil is helpful for treating the symptoms of AD	1.26 (0.6)

All measured on a 5-point Likert scale (1 = strongly agree to 5 = strongly disagree or 1= very likely to 5 = very unlikely).
Abbreviations: M, means; SD, standard deviation.

medications, which are unfortunately associated with several side effects. When managing the disease-related symptoms of AD and the side effects of medications, caregivers may seek alternative solutions as a way to alleviate these symptoms. The last few years have witnessed a growing interest in CBD oil. Previous research regarding the attitudes toward alternative options has focused on medical cannabis, but no research examining the attitudes toward CBD held by caregivers of individuals with AD has been available.

This is the first study in Poland that investigates caregivers' attitudes toward the use of CBD oil in managing the symptoms of AD. A high percentage of caregivers was satisfied with the effectiveness of CBD oil. The findings also showed that caregivers who started using CBD oil and noticed positive changes in their care-recipients' behavior had a more favorable attitude toward CBD oil than prior to using it.

While most caregivers believed that healthcare professionals should offer CBD oil as a part of treatment options, only 63 % (n = 46) reported consulting with their physician about using CBD oil. However, some of these caregivers self-reported having had an unpleasant experience and feeling misunderstood by their physicians in the open comments portion of the survey. It is possible that healthcare professionals who do not have any experience with CBD oil may react in a different way than those who have had experience. Although no studies have been conducted regarding attitudes toward CBD oil among physicians, Sharon and colleagues[40] found that physicians with prior experience in prescribing medical cannabis held different beliefs about its use than physicians without such experience. In general, physicians who prescribed cannabis viewed it as an effective and relatively safe treatment for chronic pain. It is likely that physicians who had experience with CBD oil would also differ in their attitudes in comparison to those who do not recommend CBD-based products which in the future may change the self-reported concerns of the caregivers' responses.

Another important finding is that more than a third (37 %) of caregivers administered CBD without their physician's knowledge. Educating caregivers about the dosage and potential interaction with other medications is highly important. According to a national survey, only one-third of Polish patients adhere to their physician recommendations.[41] Polish people also tend to use over-the-counter (OTC) drugs or herbal medicines.[42] OTC drugs taken in combination with prescription drugs can lead to unexpected, dangerous interactions.[43] Considering that CBD oil is a supplement and that a patient may not willingly disclose their use of CBD oil, it is important that healthcare professionals discuss this topic with their patients. Informal caregivers play a crucial role in patient treatment. Almost all individuals with AD in Poland are taken care of by family members; therefore, facilitating the communication between the caregiver and the healthcare professional will help caregivers in being able to openly discuss their concerns regarding the management of the disease.

The results of this study have important public health implications, as well. The study has highlighted the misconceptions of caregivers, demonstrated by the responses that some caregivers thought that CDB oil was illegal in Poland and that their care-recipient may develop a dependence and withdrawal symptoms if they stopped using it. Therefore, programs designed to increase individuals' awareness regarding the difference between medical cannabis and CBD are also needed. As this is the first study in Poland to assess caregivers' attitudes towards CBD oil, it contributes to the existing knowledge by demonstrating that caregivers are interested in using CBD oil but oftentimes choose not to discuss it with their physician. It also provides insight into caregivers' sources of knowledge and the barriers influencing the use of CBD oil.

If it does not exceed 0.2 % THC, CBD oil can be purchased legally in almost every European country.[44] Since there is an increasing interest in using CBD for decreasing BPS of AD among individuals, healthcare providers and policy makers across Europe should anticipate a growing prevalence of caregivers administrating CBD oil to their care-recipients. Unfortunately, health-care professionals often do not accept cannabis-derived products (including CBD) as a treatment option.[45] It is believed that a greater understanding of the use of CBD in the treatment of AD would lead to more research of its effectiveness being available, too, especially as it pertains to Poland.

It is important to implement strategies to facilitate communication between patients and health care professionals and help caregivers increase their levels of understanding of medical cannabis. It is also important to educate caregivers about the potential adverse effects related to interactions between CBD oil and the multiple medicines that a care-recipient takes regularly to treat other chronic health conditions. Discussing using CBD oil with health care professionals is also important because this product is marketed as a dietary supplement and, therefore, falls under a different set of regulations than prescription drugs. Because the government does not currently regulate the quality of products containing CBD, caregivers cannot be entirely sure of their safety. Caregivers and other customers should be aware that certain products marketed as CBD oil can be of unknown quality and potentially put customers at risk. Addressing all the above mentioned issues will help caregivers to make a more informed decision about the best course of treatment.

No research is without limitations and the researchers concede that the findings of this study have limited generalizability because the sample size was relatively small. Another limitation is that the data are cross sectional. Due to the nature of the study, caregivers who have strong opinions about CBD oil's effectiveness might have been more willing to complete the survey. Given the findings and limitations of the current study, a number of opportunities for future research have emerged. Future efforts should be made to replicate this study with a larger and more diverse group of caregivers across multiple cultures. It is also important to conduct a longitudinal study because caregivers' opinions may change over time. A longitudinal study designed to observe the effectiveness of CBD oil in managing AD symptoms during the course of the disease could extend the current line of research. Such a research design would allow researchers to examine how caregivers' perceptions of CBD oil may change and whether it impacts their own well-being. It seems that combining a quantitative and qualitative approach would allow researchers to gain more information about the experience of using CBD oil in managing the BPS of AD. Open-ended questions would allow participants to answer the research items using their own words, rather than choosing from one of the pre-formulated responses which might also bring some unique and unexpected responses that could lead to new findings that might otherwise never have emerged if the participants were only able to select from one of the predefined answers.

Considering the ubiquitous presence of CBD in products including food and drinks, and the fact that benefits of CBD are being recognized for a number of medical conditions, it is imperative that health systems, physicians, policy makers, patients, and caregivers all become familiar with its uses. A growing of body research has demonstrated that CBD has been shown to be effective in the treatment of epilepsy,[46] spasms associated with multiple sclerosis,[47] and anxiety-related disorders.[48] All of these disease entities are common among older adults. Aside from neurocognitive disorders, CBD has increasingly shown benefits in other conditions common in older adults - cancer and arthritic pain, chemotherapy induced nausea, and cancer cachexia as it is more widely prescribed. Given this information, it behooves everyone involved in the delivery of care to older adults to stay abreast of current developments in the use of CBD.

The results of the study highlight the different perceptions of caregivers toward the use of CBD oil in patients with AD. While mostly positive about CBD use and its results, there were some concerns expressed as well. The study also emphasizes the importance of enhancing communication between caregivers and healthcare professionals to discuss the use of CBD oil in the treatment of individuals with AD.

CRediT authorship contribution statement

Magdalena Leszko: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Writing - original draft, Writing - review & editing. **Senthil Meenrajan:** Conceptualization, Methodology, Writing - review & editing.

Declaration of Competing Interest

The authors report no declarations of interest.

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