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Toward a Patient Registry for Cannabis Use: An Exploratory Study of Patient Use in an Outpatient Health-Care Clinic in Oregon

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INTRODUCTION

State level initiatives legalized and or decriminalized non-medical marijuana use in Colorado, Washington, Oregon, Alaska, the District of Colombia, California and Nebraska. Twenty-eight other states and the District of Columbia allow medical cannabis use. Nationally, cannabis use more than doubled between 2001–2002 and 2012–2013 with corresponding increases in cannabis use disorders (Hasin DS et al. 2015). Given changing laws, usage and attitudes toward cannabis, concerns are being raised about the impacts policy changes may have on individual and community health and well-being (Lipari, Kroutil, and Pemberton 2016; Volkow ND et al. 2016).

Cannabis contains numerous cannabinoids; its use has been associated with both health risks and benefits (Hill 2015). Studies suggest that use of cannabis can negatively affect respiratory function and cardiovascular function, and may interact with prescribed medications (Hall and Degenhardt 2009; Jones 2002; Mittleman et al. 2001; Owen, Sutter, and Albertson 2014; Polen et al. 1993; Tashkin 2013; Thomas, Kloner, and Rezkalla 2014). Additionally, data suggest that the use of cannabis is associated with other substance use

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disorders (Blanco C et al. 2016). On the other hand, cannabis may help individuals with chronic pain, neuropathic pain and spasticity due to multiple sclerosis (Whiting PF et al. 2015; Hill 2015). There is, however, little prospective, longitudinal data on the health, and healthcare utilization associated with chronic cannabis use. A patient registry of cannabis users linked with their electronic health records could provide insights into the medical benefits and consequences associated with cannabis use.

A patient registry is “an organized system that uses observational study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure, and that serves one or more predetermined scientific, clinical, or policy purposes” (Gliklich, Dreyer, and Leavy 2014). Patient registries provide the opportunity to conduct research on patient outcomes related disease, condition, exposures, or product use. Registry information differs from clinical trials in that it relies on electronic health records which capture patient data, and facilitates investigation of associations with healthcare utilization and health outcomes.

Patient registries played a critical role in the generation of evidence regarding cigarette smoking and lung cancer, as data documented high rates of lung cancer prevalence in smokers (Jemal et al. 2013), declining incidence rates of cancer in states with declining rates of users (Centers for Disease Control and Prevention (CDC) 2011; Cokkinides et al. 2009; Jemal et al. 2003; Pierce et al. 2010), and the overall declines of smoking rates and lung cancer rates (Centers for Disease Control and Prevention (CDC) 2011). Evidence of the harms of tobacco promoted policy changes that improved population health.

The creation of a patient registry, however, is a complex task. When creating a registry for a product that has myriad forms and methods of use such as cannabis, it is critical to begin early in the registry development process with an ethnographical approach that investigates the kinds of questions (and response options) that are relevant within the registry. Without a thorough understanding of patients’ reasons for use, perceived effects and routes of administrations, registry variables may reflect a researcher’s antiquated or ill-informed conceptions of modern cannabis use.

As legalization spreads across the country, it is likely that patient cannabis registries linked to electronic health records may be developed to assess long-term consequences of cannabis use. Additionally, because non-medical cannabis users may differ from medical cannabis users, it is important to also develop cannabis use registries in communities where non-medical use is permitted. To begin the development of a cannabis use registry in Oregon, a small sample of users were interviewed to better understand patient perspectives about their motivations for using cannabis, methods of use, perceptions about benefits, and concerns about risks.

METHODS

An open-ended, semi-structured interview guide examined cannabis use, route of administration (e.g. smoked or inhaled, ingested, topical), and perceived health benefits and risks of cannabis use. Data were collected at an outpatient healthcare clinic in Portland,

Oregon for a period of one month. Signs were posted in the clinic's reception area announcing the opportunity to participate in a study on cannabis if they had used cannabis twice or more in the past month; patients volunteered to participate when they checked-in for a previously scheduled medical appointment. Lack of remuneration did not appear to impact patients' willingness to participate. Receptionists explained that patients may participate either before or after their appointment. The original sample size was projected to be 20 or until saturation of responses was reached. Twenty-two patients were recruited (12 female, 10 male, 20 to 64 years of age).

Non-medical use of cannabis became legal in Oregon on July 1, 2015 and all interviews were conducted during July and August, 2015. The Oregon Health & Science University Institutional Review Board reviewed and approved the research protocol.

Interviews

Interviews were conducted in a closed, private office by trained qualitative interviewers. Study participants were informed that their answers were confidential and would not be recorded in their medical chart. The interview guide contained open-ended questions about current and past use of cannabis, methods of use, perceptions and attitudes toward use, impact of use on health, and perceived benefits and harms of use. Probes were used as needed. Sample questions illustrate interview items: How frequently do you use cannabis or cannabis products? In what ways do you use it (probes: smoking, eating, etc)? Have you noticed any health impacts as a result of use or non-use? Have your attitudes changed about your use over time? If so, how/why? Interviews ranged from 20 to 40 minutes and patients were not compensated for their time. Given the "surprise" nature of the interview (patients did not know prior to their regularly scheduled clinic appointment of the opportunity to participate in the study) and to increase patient comfort level, interviews were not audio recorded and interviewers took extensive notes with direct quotes and summaries of responses. After each interview, the notes and quotes were discussed by at least two study team members and a single refined, de-identified summary document for each interview was created for analysis.

Analysis

Interview summaries were circulated to each member of the team for review. Two investigators developed an initial coding scheme based on team discussions and reviewed it with the rest of the team. The same two members of study team collaboratively developed and prepared a final coding scheme and completed the qualitative analysis using a constant comparative and content analysis approach (Krippendorff 2004). Qualitative analysis grouped respondent comments into three top-level themes: 1) methods of use, 2) purpose and benefits of use and 4) adverse consequences of use.

RESULTS

Quantitative data on demographic and substance use characteristics of participants ($n = 22$) is summarized in Table 1. The majority of participants were women (55%). Ages ranged between 20 and 64 years, with 28 to 39 years being the most common category. Initiation of

use usually began as “experimental” and “social” in high school, turning to “medicinal” in adulthood. Patients (21 of 22) reported using for psychological distress, physical pain, or both. Respondents aged 30 and older reported that they used for non-medical purposes when younger but currently used strictly for health related reasons. Cannabis products and routes of administration varied widely. The following summarizes the results of the qualitative interviews, grouped according to the three themes of 1) purpose and perceived benefits of use, 2) methods of use, and 3) adverse consequences of use.

Purpose and perceived benefits of use

Respondents reported significant benefits from using cannabis for health concerns such as fibromyalgia, post-traumatic stress disorder, anxiety, migraines, neuropathic pain, glaucoma, alcohol and opiate addiction recovery, eating disorders, connective tissue disorders, nausea, menstrual cramps, spinal stenosis and joint pain. Patients reported using cannabis mostly for “medicinal” purposes or specifically for a health condition, as opposed to non-medical use. For example, a woman 55 years of age stated: *“My days of getting high are long gone”*. Just under half of the study sample had a medical cannabis card. Of those who did not, some expressed that they would like to pursue that option but could not afford to pay for the fees associated with the procurement of the card such as the medical consultation. A 64 year-old woman with a previously light history of cannabis use received her medical cannabis card 8 months prior to being interviewed. She stated: *“I did my homework. I looked into it a lot before asking for a card”*. She mentioned that her attitudes toward cannabis had changed significantly over her lifetime: *“It was illegal! I used to be a goody two shoes. I saw people who had problems with cannabis just like alcohol. But I’ve come to realize that there are a lot of things about the marijuana plant that are good - it can be used medically”*. In general, respondents expressed an interest in having more robust information about dosage and components of cannabis so that, as one respondent put it, *“I can know what I am taking and calibrate it.”*

Relief from Drug and Alcohol Cravings—Some stated their cannabis use was linked to trying to curtail drug and alcohol cravings. Specifically, several study participants claimed that they obtained major relief from opioid cravings as a result of cannabis use and that it enabled them to resist seeking heroin, oxycodone or other opioids. A 34 year-old man, dependent on oxycodone after being prescribed the medication for a shoulder injury, used cannabis to “kick” the addiction and has remained opioid-free for three years despite continued cravings: *“I still want it [oxycodone] coursing in my blood to this day”* but observed he doesn’t want that “lifestyle”. He found that during his six weeks of self-detoxification from oxycodone, smoking cannabis alleviated his severe withdrawal symptoms. A 64 year old woman began using cannabis preemptively for opioid dependence; she started using prescribed hydrocodone at age 18 and used it *“intermittently but constantly throughout my life”*. As she aged, she began to need higher doses due to a poorly performing knee replacement and arthritis in addition to debilitating migraines: *“I have seen too many people become addicted [to hydrocodone]. I didn’t want that”*. After a period of research with the help and support from her family, she sought a medical cannabis card and switched from hydrocodone to cannabis to reduce her chronic pain. She believed she achieves the same relief from her pain as with hydrocodone.

Relief from Physical Pain—Other respondents reported achieving relief from pain due to work and sports-related injuries. For example, a male patient started using cannabis in 2009 for back pain as recommended “*off the record*” by his physician. A 39 year old woman stated: “*I’m just trying to survive and this is one thing that works but it is a final option, when I have tried everything else and at wits end, I smoke a little and it alleviates the pain*”. Interestingly, some reported feeling physiologic relief from pain while others said that they weren’t convinced cannabis actually alleviated the pain as much as it helped take their mind off of it: “*Pot doesn’t help with inflammation, doesn’t help with pain, but helps me zone out and concentrate on things other than the pain*”. A woman shared her experience: “*When I am in excruciating pain it doesn’t get rid of it but it helps me to not be so freaked out about the pain. It helps me from getting agitated, helps me calm down*”.

In a particularly interesting case, a 42 year-old man reported he used hash five to six times a month for pain management. Long abstinent from street use of heroin, cocaine, analgesics, and alcohol, for the past 15 years he had been receiving prescriptions for 160 mg of methadone daily from his primary care provider. When new office protocols required his being weaned to 60 mg daily, he felt he needed additional pain relief. Instead of buying heroin or methadone off the street, he began to smoke hash. “*One hit*” was sufficient to alleviate his pain. He does not smoke cannabis buds because he does not like the high - he would “*love*” to have a hash that is low in THC, as he experiences “*guilt*” if he begins to feel a high. He is a member of Alcoholics Anonymous (AA) and is open about his hash use with his sponsor and peers in AA. Some think he is “*cheating*” but he explains his rationale and “*most get it*”. The hash diverts his thoughts away from craving harder drugs: “*It [cannabis] takes me out of my mind, from doing something stupid*”. When he has thoughts of using heroin or other drugs, he “*smokes a bowl and goes to sleep*”. He claimed a long and severe history of physical and sexual abuse, criminal activity and homelessness. He is now stable, has housing, and is determined not to return to his old life. He felt that cannabis enabled him to stay off the harder drugs that led to bad decisions and outcomes.

Relief from Psychological Pain—Women and men observed that they experienced relief from depressive, anxious or scattered thoughts as a result of using cannabis: “*I don’t know where I’d be without it*”. Several reported that cannabis held suicidal ideations at bay; a 49 year-old woman said bluntly: “*it keeps me from killing myself*”. A young man stated that he has been diagnosed with attention deficit disorder and been on “*every antidepressant*”. He reported that the antidepressants “*make me angry and give me suicidal thoughts*” whereas with cannabis, he can “*focus, read a book, can study for my GED [General Education Development]*” without the negative side effects of the pharmaceutical drugs he had previously been prescribed. A 25 year-old woman observed that “*weed doesn’t help with my suicidal thoughts but helps me come back to earth*”. Another, who reported having post traumatic stress disorder, used cannabis in conjunction with cognitive therapy because it “*dampens the anxiety and allows me to work things out without having a really acute stress response*”. In contrast, a 39 year-old man said that he specifically does not use cannabis as a stress reliever because “*there are better ways to manage stress. In my family there is a tendency toward addiction so I’m very introspective about my use. So I always ask myself, am I arranging my life so that I can use this drug?*” Most study participants believed

that cannabis was relaxing and slowed them down. Two, however, reported that it gave them more energy. Three women noted that cannabis stimulates them to have a healthy appetite and overcome poor eating habits. A 21 year-old woman said: *“I don’t have an appetite so I eat small amounts of food and if I smoke it helps me eat healthy amounts”*. Another woman with a history of bulimia said that cannabis helps her to *“reset my eating habits, so I could eat in public, and don’t get neurotic or close to overeating”*. Three women reported that they used it for nausea.

Methods of Use

A wide variety of methods of using cannabis were reported, each with its own nuanced experience such as taste and smell (or lack thereof). Inhalation through smoking and vaping was the most common method. Products smoked or vaped included “buds”/“flowers”, hash, oils, resins, “dabs” (*“looks like caramels; comes on wax and then you break it off and smoke it”*) using pipes, bongs, vaporizers or “knife hits” (warm up a knife, place on the “dabs” or the resin and inhale the smoke with an instrument specific for this purpose or toilet paper roll). Vaporizing either oils, resins or “flowers”/“buds” was the most common method after smoking. The use of “edibles” (food products) was common and included smoothies, candies (gummy bears, hard candies), butter infused with cannabis, cannabis buds boiled in milk to make a tea, and baked products, usually brownies. Not commonly used but reported were swallowing capsules or tablets. Several respondents used topical ointments (i.e., lotions, oils and salves) for muscle and joint pain.

Respondents reported that effects and benefits varied by method of use; there was little consensus about preferences. Most respondents felt vaporizing was healthier than smoking as there weren’t *“particulates getting into my lungs”*. Of those who consumed edibles, most felt they were more effective for pain relief than smoking. A 64 year-old woman ingested a *“glycerin that is high in CBD low in THC”* and reported that the product worked on headaches, anxiety and general pain: *“it’s sweet but tastes gross”*. Her preferred edible was a hard candy called “Schrapple” which she kept in her purse and used discretely in public as needed.

Adverse consequences of use

Respondents perceived few adverse consequences to using cannabis and felt that the benefits outweighed the risks. None felt they had an addiction to cannabis, though two reported they were cautious users, fearing addiction. A recovering alcoholic expressed concern that smoking could act as a gateway drug for him to start drinking but that he is very introspective and conscientious about his use and has remained abstinent from alcohol to date. Additionally, two respondents were concerned about addiction potential in the general population: *“Pot is a gateway drug for people, just like nicotine and alcohol”*. Some felt the message expressed by the recent legalization movement was problematic and they worried about individuals using *“too early in life”* which *“impairs attention and ability to learn”*. For patients with injuries who used cannabis for pain relief, several reported that the pain relief itself could be problematic, leading to a lack of awareness about their body’s limitations: *“Pot can make you forget the pain too much and not be careful, for example, with my shoulder”*.

Most respondents who smoked cannabis expressed concern about pulmonary health – carcinogens, particulates, or the act of “*introducing carbonized materials into lung tissue*”. A 44 year-old man with asthma reported that he did not smoke at all while having an asthma exacerbation as he was concerned about aggravating his condition. He noted that after he quit smoking tobacco, his intake of cannabis increased. A 21 year-old woman who smoked cigarettes said she was concerned that her morning phlegm may be attributable not just to smoking tobacco but also smoking cannabis. A 38 year-old woman who smoked reported that cigarettes enhanced the effects of cannabis and “*makes cigarettes taste better*”.

One respondent with anxiety was unsure if he was experiencing negative psychological consequences due to his innate nature or if it was related to cannabis use. He noted that his severe anxiety and panic attacks predated any cannabis use and that when he cut back on using cannabis, the frequency of his panic attacks increased. A 45 year-old man used cannabis to relieve anxiety, but after years of use, it now makes him anxious. Another reported that she can have depressive feelings when using cannabis: “*I have major depressive disorder and it [cannabis] doesn’t work well with it. It makes me isolate*”. She also struggled with anorexia and expressed that “*It helps with appetite and to have the desire to eat but then I’m too lazy to get up to eat*.” Others reported that cannabis had increased their appetite and led to unwanted weight gain.

DISCUSSION

Despite its prevalence, cannabis use gets little attention in primary care settings.. Clinical screening for alcohol, tobacco and other drugs often glosses over cannabis use. Adverse health effects have been associated with cannabis use, including cognitive impairment and reduced functional neural connectivity when use begins in adolescence, chronic bronchitis, and increased risks for psychosis and addiction (Volkow et al. 2014). Researchers do not have access, however, to important prospective, longitudinal data on the associations between a wide range of health indicators and long-term cannabis use – the kind of data patient registries offer when linked to electronic health records. Traditionally, medical cannabis use registries simply include the patient’s specific, qualifying medical reason for use; our model would expand this to include self-reported cannabis use in the electronic health record to tracked associated patient outcomes over time.

As a preliminary stage to developing a patient registry of cannabis users in Oregon, 22 cannabis users were interviewed in an outpatient healthcare clinic to better understand how and why they use cannabis products. Participants reported a variety of methods for ingesting cannabis products; inhaled, ingested and topical. Less than half of the subjects reported being registered in the Oregon Medical Marijuana Program (OMMP), yet, all but one described using cannabis products for relief of medical symptoms. Given that the OMMP is only available for 1) individuals with a specific, qualifying medical condition, 2) a recommendation for medical marijuana from an attending physician and 3) those who can afford the registration fees, some patients may be unable to access it.

This study was an exploration into the variables – the specific question and answer categories – that a cannabis registry might include. Simply asking a patient, “Do you smoke

cannabis?” for a cannabis registry provides an incomplete picture of contemporary use patterns. For example, about half the patients used methods other than the traditional method of smoking buds/flowers; they vaporized resin, dabs and oils, ate candies, brownies and butters, and used gels and creams as topical analgesics. Additionally, given the respondents wide range of reasons for cannabis use, a registry should contain answer question and categories that cover include physiologic and psychologic pain relief. In our sample, patients most commonly reported seeking relief for symptoms for pain and anxiety. At times cannabis use was viewed as a replacement for opioid analgesics, an important finding worthy of further exploration. Lastly, how patients use may increase or reduce risk of adverse health consequences; a registry that does not include response categories for the wide variety of methods will fall short in providing answers to questions about how different methods affect health over time. Many patients are using cannabis for perceived health problems and there is a need for long-term, empirical data rather than patient anecdote on medical benefits and harms related to chronic cannabis use.

Patient registries can assess the natural history of health conditions, test the relative and cost effectiveness of interventions, monitor safety, examine healthcare variation and disparities, and monitor healthcare quality (Gliklich, Dreyer, and Leavy 2014; Tai et al. 2014). A cannabis registry addresses the need for more data on the association between cannabis and health status and provides a foundation and infrastructure for more complex registry studies. Patient registries of cannabis users can begin to build patient cohorts and enable studies to assess the associations between health status, healthcare utilization and cannabis use.

Limitations

The findings are limited by use of a small, convenience sample of volunteers in a single clinical setting, some of whom may have biases about use of cannabis products. The timeframe of the study was constrained to four weeks so that disruptions to the clinic were kept to a minimum. Data collection was conducted during the first two months of cannabis legalization in the state of Oregon. Lack of certainty about the legal implications of discussion cannabis use may have suppressed recruitment efforts.

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Table 1

Characteristics of Participants and Cannabis Use (n=22)

	N (%)
Gender	
Male	10 (45%)
Female	12 (55%)
Median age (year)	38 years
Age Range	
Under 28	3 (14%)
28–39	9 (41%)
40–55	6 (27%)
Over 55	3 (14%)
Has Medical Marijuana Card	10 (45%)
Medicinal vs. recreational use	
Recreational only	1 (5%)
Medicinal only	15 (64%)
Both	7 (32%)
Condition reported as reason for use	
Musculoskeletal pain	13 (59%)
PTSD	6 (27%)
Stress	4 (18%)
Depression	4 (18%)
Anxiety	4 (18%)
Cravings from previous opioid use disorder	3 (14%)
Nausea	3 (14%)
Eating disorder	3 (14%)
ADHD/ADD	3 (14%)
Neuropathic pain	2 (9%)
Migraine	2 (9%)
Insomnia	1 (5%)
Bipolar disorder	1 (5%)
Product Type	
Buds/Flowers	17 (77%)
Oils	2 (9%)
Tablets/Capsules	2 (9%)
Ointment	2 (9%)
Leaf infusion	1 (5%)
Infused butter	1 (5%)
Candies	1 (5%)
Glycerine	1 (5%)

	N (%)
Method of Administration	
Smoked	16 (73%)
Ingested	7 (32%)
Vaporized	5 (23%)
Topical	2 (9%)

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