Cancer Patients' Experiences With Medicinal Cannabis-Related Care

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BACKGROUND: Little is known about medical cannabis (MC)-related care for patients with cancer using MC. Methods: Semistructured telephone interviews were conducted in a convenience sample of individuals (n = 24) with physician-confirmed oncologic diagnoses and state/district authorization to use MC (Arizona, California, Florida, Illinois, Massachusetts, Oregon, New York, and Washington, DC) from April 2017 to March 2019. Standard qualitative techniques were used to assess the degree of MC-related health care oversight, MC practices, and key information sources. Results: Among 24 participants (median age, 57 years; range, 30-71 years; 16 women [67%]), MC certifications were typically issued by a professional new to a patient's care after a brief, perfunctory consultation. Patients disclosed MCuse to their established medical teams but received little medical advice about whether and how to use MC. Patients with cancer used MC products as multipurpose symptom management and as cancer-directed therapy, sometimes in lieu of standard-of-care treatments. Personal experimentation, including methodical self-monitoring, was an important source of MC know-how. Absent formal advice from medical professionals, patients relied on nonmedical sources for MC information. Conclusions: Patients with cancer used MC with minimal medical oversight. Most received MC certifications through brief meetings with unfamiliar professionals. Participants desired but were often unable to access high-quality clinical information about MC from their established medical teams. Because many patients are committed to using MC, a product sustained by a growing industry, medical providers should familiarize themselves with the existing data for MM and its limitations to address a poorly met clinical need. Cancer 2021;127:67-73. © 2020 The Authors. Cancer published by Wiley Periodicals LLC on behalf of American Cancer Society. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

KEYWORDS: cannabis, complementary therapies, health communication, marijuana use, medical oncology.

INTRODUCTION

More than 2 million United States residents use cannabis for medicinal purposes in compliance with state law. Although the 34 state comprehensive medical cannabis (MC) laws vary dramatically, most require a physician visit, including a thorough medical assessment and weighing of risk-to-benefit ratios, for the initial MC certification and evidence of longitudinal care for renewals. Because cancer is a qualifying condition for MC certification under almost all state laws, oncology offers a relevant model for investigating the clinical impacts of these laws and serves as the focus of this study.

Even as MC laws identify cancer as a qualifying condition, sparse clinical trial evidence supports the use of whole-plant cannabis in oncology. The few existing randomized clinical trials of full-spectrum MC demonstrate that it may improve chemotherapy-induced nausea and vomiting.²⁻⁴ Studies also show that patients with cancer use MC and oncology clinicians turn to it clinically to ameliorate cancer pain, poor appetite, sleep disturbance, fatigue, anxiety, and poor coping and as cancer-directed therapy.⁵⁻¹⁰

Relatively little is known about MC clinical processes, including how patients access MC-related information and how MC decisions are made. Early evidence suggested challenges with the integration of MC into oncologic care. For instance,

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See editorial on pages 27-30, this issue.

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a recent survey of patients with cancer found that a quarter relied on cannabis (MC or otherwise) to manage symptoms, including pain, nausea, poor appetite, and "stress," but less than 15% received cannabis-related information from their medical providers. In a national survey of US oncologists, we found that, although many oncologists recommended MC to their patients (eg, for appetite, pain, and nausea), most did not trust their MC-related knowledge base, and these finding have been replicated. 8,11

In the current study, we interviewed a geographically diverse US sample of oncology patients using MC (n = 24) and explored their experiences with the agent. Here, we focus on the subset of those experiences pertaining to the nature of MC integration into health care, particularly the degree of MC-related health care oversight that participants encountered, their key sources of MC information, and their practices regarding MC use.

MATERIALS AND METHODS

Recruitment and Participant Selection

Researchers selected 8 geographically and culturally diverse states/districts with permissive MC legislation: Arizona, California, Florida, Illinois, Massachusetts, Oregon, New York, and the District of Columbia. Through Google searches, they identified state-sanctioned MC dispensaries in those states and contacted 61; 27 (44.3%) agreed to distribute study advertisements through their storefronts. Dispensaries that refused participation reported doing so because they served few clients with cancer or sold only recreational cannabis.

At checkout, participating dispensaries offered a study flier, "Please Tell Us About Using Marijuana for Cancer," to all clients, regardless of their diagnoses. The flier briefly described the study, eligibility criteria, and study-related compensation (\$75). After confirming that interested individuals were certified to use MC in compliance with state law, dispensary staff provided potential participants with contact information for study personnel. Researchers screened by phone interested individuals to confirm that they met eligibility criteria and mailed those who did a written informed consent form. As part of the consent process, study participants agreed to allow researchers to 1) contact a physician on their medical team to verify their cancer diagnosis and 2) audio-record the telephone interview. Between April 2017 and March 2019, recruitment occurred in phases to ensure adequate capture of emergent themes.

Eligibility criteria included the following: being 18 years old or older, a US resident, and English-speaking; having a health care provider-verified history of cancer;

having state authorization to procure MC; and being willing and able to complete a 45-minute interview. The sampling strategy focused on recruiting information-rich cases; purposeful sampling procedures were aimed at capturing geographic and demographic diversity as well as a broad array of cancer types and stages. ¹² For example, a maximum of 5 individuals were included per state, and patients out of active cancer treatment or in cancer remission were included. Data collection ceased when meaning saturation was achieved. ¹³ This study was approved by the Dana-Farber Cancer Institute institutional review board.

Instrument Design and Data Collection

The primary investigator (I.M.B.) along with 2 qualitative methodologists (M.M.N. and A.R.) designed a draft semistructured interview guide. They presented the draft to a multidisciplinary group that reviewed it for completeness and comprehension. Edits to the interview were incorporated, and the guide was returned to the group for final approval. A trained researcher (M.M.N.) conducted audio-recorded, semistructured interviews that were transcribed verbatim and de-identified.

Analysis

A qualitative research expert (A.R.) coded and analyzed transcripts by using a multistage thematic analysis that combined prefigured and emergent codes and incorporated aspects of grounded theory and more applied framework analysis. 14-17 Established domains from a literature review and interview guide provided the codebook's initial framework. An inductive open-coding approach was next applied to transcripts, and emergent concepts were added to finalize the codebook. NVivo 12 (QSR International) facilitated manual transcript coding. A comprehensive analysis focused on the description and interpretation of interview data and on the drawing of comparisons across interviews to define unique challenges that MC use poses in the context of overall health care. ¹⁷ Each stage of coding and analysis was iteratively designed, discussed, and verified by a 3-person interdisciplinary research team (I.M.B., M.M.N., and A.R.) to address trustworthiness in approach and interpretations. Data collection ceased when interviews stopped yielding new meaningful information, and it was determined that meaning saturation was achieved. 13,18,19

RESULTS

Among 67 individuals interested in study participation, 17 did not meet eligibility criteria, 18 lived in states already sampled, 2 were lost to follow-up, and 2 declined; 3 of the 28 remaining individuals could not be reached, and

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TABLE 1. Self-Reported Participant Characteristics (n = 24)

Characteristic	Value
Sex, No. (%)	
Female	16 (67)
Age, median (range), y	57 (30-71)
Ethnicity, No. (%) ^a	
Non-Hispanic/non-Latino	19 (79)
Hispanic/Latino	4 (17)
Race, No. (%)	
White	19 (79)
More than 1 race	2 (8)
African American	1 (4)
Asian	1 (4)
Declined to answer	1 (4)
Education, No. (%)	
Some college or more	18 (75)
High school or less	6 (25)
Work status, No. (%)	
Disabled	9 (38)
Working	6 (25)
Retired/unemployed	5 (21)
Other	4 (17)
Marital status	
Married/cohabitating	13 (54)
Divorced/widowed/single	11 (46)
US region, No. (%)	
Eastern	11 (46)
Western	7 (29)
Midwestern	6 (25)
Cancer type, No. (%)	
Breast	7 (29)
Gastrointestinal	5 (21)
Other	12 (50)
Cancer stage, No. (%) ^b	
Early stage	8 (33)
Advanced stage	12 (51)
Remission	4 (17)

^aOne person declined to answer this item.

1 died before the interview. Ultimately, 24 individuals from 7 states and the District of Columbia participated in an interview. Table 1 displays the sample's characteristics. Sixteen participants (67%) were women, and the median age was 57 years (range, 30-71 years). Eleven participants (46%) resided in the Eastern United States, 7 (29%) lived in the Western United States, and 6 (25%) lived in the Midwestern United States. Seven (29%) had breast cancer, 5 (21%) had gastrointestinal cancers, and 12 had a range of other cancers. Twelve (51%) reported that their cancers were metastatic or incurable, 8 (33%) had early-stage disease, and 4 (17%) were in remission. Table 2 displays key themes and exemplar quotations.

Theme 1: Most Participants Received MC Certifications Through Brief, Perfunctory Meetings With Unfamiliar Professionals

All but 1 of the participants offered information about their MC certifier. For 17 participants, the certifier was

not previously a member of their medical team. For the other 6, a member of their established medical team (eg, a primary care physician, oncologist, or other specialist) issued the official recommendation to the state.

Nineteen participants discussed the certification process in detail (the other 5 did not comment). Eleven described brief and transactional interactions with their certifier (for 10, the certifier was new to their care). Generally, these visits included a payment and short discussion, mainly pertaining to government paperwork, before a recommendation was made. For example, 1 participant received an MC card after a Skype call with a physician's assistant and a 10-minute in-person visit with the physician certifier. The other 8 of the 19 participants reported more involved visits (eg, a physical examination and discussion of MC strains and ratios of active ingredients; for 5, the certifier was part of their established medical team). Although the nature of these visits varied from person to person, topics that might be discussed included appropriate indications, MC strains, modes of use, alternatives, and preferred MC dispensaries.

Seventeen of the 23 participants who offered information about their MC certifier also commented on follow-up visits. Nine of these reported having the minimum follow-up contact required for state renewals, 5 denied follow-up, and 3 reported ongoing interactions with their certifier because that individual was a member of their established medical team.

Theme 2: Patients Disclosed MC Use to Their Established Medical Teams but Received Little Advice

All study participants reported discussing MC with their primary medical team at some point in their care. Twentytwo were open about their use, whereas 2 raised the topic but did not explicitly state that they used MC. Participants noted that most medical providers responded neutrally; however, for a third of the participants, at least 1 of their medical providers (including oncologists, primary care physicians, psychiatrists, radiologists, and neurologists) responded favorably. Negative responses were less common (eg, they were explicitly reported in only 6 instances) and included medical providers who reported being "against MC," doubted MC's impact, wanted "to hear nothing about it," or leveled an accusation of substance abuse. Among the 17 patients with a MC certifier outside their established medical team, none described communication between their certifiers and their established medical teams.

In instances in which the MC certifier was not a member of the patient's established medical team, a

^bAdvanced stage indicates stage IV or metastatic.

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TABLE 2. Key Themes and Exemplar Quotations

Themes	Subthemes	Exemplar Quotations
Most participants received MC certifications through brief, perfunctory meetings with unfamiliar professionals.		"The guy wore a stethoscope and never used it. Nor did he examine me in any way, nor did he ask any really penetrating questions. I went in, gave the guy my \$200 I spoke to the doctor who said 'What ails you?' 'Cancer ails me.' Okay, sign on the dotted line, and I was out the door Helping me figure out what I needed and how to go about the process of self-medicating? None of that was provided by—by this doctor." (Participant 101) "Once he handed me the paper to say that I was approved, I looked at the boxes that he was checking, and it was talking about, like, vital signs, and, you know, like, if my stomach was distended or—I mean it just had all these things that he never did any sort of exam or anything. It was more he just asked me why I wanted to do it and that was it." (Participant 102)
Patients disclosed MC use to their established medical teams but received little advice.	Transparency with medical providers about MC	"They wrote me the prescription, but they were unwilling to give any sort of advice in terms of how much and what kind." (Participant 122 "You're supposed to tell your doctor everything, and, you know, whatever drugs you're taking, and I just figured it was the right thing to do." (Participant 112)
	Negative responses from medical providers	"Most doctors—you mention cannabis: They shut right up. They don't say two words to you. They don't give you an opinion: Nothing. They just shut right up." (Participant 112) "All I got from the—clinic was 'Well, do you have evidence? Do you have actual research in front of you?' And I said, 'No, I did not bring my book of information, but I do have information, and most likely more than you do." (Participant 134)
	Little MC-related medical advice from established medical providers	"I told them I was doing it and stuff, and I asked some suggestions and what it comes down to is they—they just don't know about the marijuana." (Participant 102) "[They] weren't confident or comfortable recommending different types or different dosages to me, given that they didn't know enough about it, and there wasn't enough research. They said that they didn't believe that it was harmful but didn't fully understand how helpful it was either." (Participant 122) "I vaped in front of my doctor the other day and he didn't even know what I was doing." (Participant 140) "They didn't say nothing about. They don't give any advice and haven' spoken to me, really besides, about MC at all." (Participant 155)
	Patients with cancer serving as edu- cational resources on MC for medical providers	"I gave him all of the information that I had on [MC] and I ended up talking to a couple of his patients and he said, would you mind because he said, they had questions." (Participant 130) "I was the first one to bring it to her, so and it was a learning experience for her as well." (Participant 134) "He would appreciate any progress reports on it, becausethey are interested in the application of it, and they wanted to see." (Participant 140)
Self-monitoring served as an important source of MC know-how.	Methodical self-monitoring	"I'm documenting quantities, I'm looking at how I feel, I'm documenting how long it takes before I feel, you know, pain relief, or before I nod out and go to sleep. How do I feel when I wake up? You know, all those things, I've documented I'm experimenting. And—and depending on—see, I have a table. I'm building up, okay, how much THC is in this brand? This strain that I just purchased. And then is it an indica, or is it a sativa? Put that—put that checkmark in the table." (Participant 101) "We monitored closely how quickly it runs into my blood stream. I'm not sure if for everybody it's different but it takes me about an hour or an hour and a half to feel the full effect." (Participant 164) "So I did a sensitivity test, and they—and I sent in some [Rick Simpson Oil] and found that the [Rick Simpson Oil] does kill my can cer cells So now I know that [Rick Simpson Oil] really works What I do is in the morning, I'll just make a little capsule and I'll put a little grain of rice sized in there. Because I keep it very minimal in the day because I don't like the high, but what I found is you can use [cannabidiol] oil after you take it and it buffers it. So that helps a lot, a whole lot. And I usually will take depending on pain levels or how I feel or what I'm doing, you know I might take a midafternoon dose and then I take one before I go to bed. But I've been mixing

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TABLE 2. Continued

Themes	Subthemes	Exemplar Quotations
	Imprecise measurement	"The [chocolate] bars were 100 mg of marijuana, and so I would try to break it up and, like, estimate, you know, somewhere like the 6 or 7 [mg] range or so." (Participant 103)
		"Scraped a chunk probably the size of my pinky nail maybe, you know what I mean?" (Participant 112)
Patients relied on nonmedical and an- ecdotal sources for MC information.		"The naturopaths don't really have that much information on it like the dispensaries do. That's where I get my information, really. It's online or the dispensaries." (Participant 133)
		"Sometimes I go in and I ask [the MC dispensary employee] additional questions. Like, I say, 'You know, one of the things I'm having, I had a problem with: muscle spasms' I mean, they have a better feel from the reaction that other buyers have had while they've gone through there." (Participant 101)
Patients with cancer used MC for multipurpose symptom management and as cancer-directed therapy.	MC as cancer-directed therapy	"I think people had read different research projects and something that marijuana can kill cancer cells, and so people have recom- mended it to me from that perspective, and then people also rec- ommended it to me for, like, sleeping and anxiety." (Participant 103)
		"I had watched a documentary about cannabis and cancer, and I made a decision right then and there I wasn't going to touch chemo and I wasn't going to touch radiation and I never did." (Participant 112)

Abbreviation: MC, medical marijuana.

theme recurred of members of the established medical team being unwilling or unable to offer clinical recommendations regarding MC either because they did not want to involve themselves in MC decision making or because they did not consider themselves knowledgeable enough to do so. Recommendations from noncertifying medical providers about active ingredients, dosing, routes of administration, and risks and benefits were vague and rare: one physician favored vaporization over smoking; a second cautioned against MC use because of the participant's fragile health; a third indicated general concern about drug-drug interactions; a fourth warned against stopping prescribed medications in the setting of MC; and a fifth recommended a health care provider with MC expertise. Some participants reported that they served as educational resources for curious medical providers who hoped to help other patients with information gleaned from the participants' experiences with MC.

Theme 3: Self-Monitoring Served as an Important Source of MC Know-How

An emergent theme was experimentation with ratios of active ingredients and routes of administration (eg, "It's all trial and error"). Participants frequently alternated between tetrahydrocannabinol- and cannabidiol-rich strains according to their target symptoms. In the total sample, routes of administration included consuming edibles or taking MC sublingually (n=22), vaporizing MC (n=16), smoking MC (n=13), applying MC topically (n=6), and using MC as a rectal suppository (n=3). Fifteen

reported using more than 2 routes to administer MC, and 6 reported more than 3.

Several participants practiced rigorous self-observation regarding MC use ("I document my consumption"). Six carefully tracked the amplitude of their highs and used them to titrate the dose, whereas others tracked negative side effects, including ataxia, cognitive compromise, and hypersomnolence. One used a blood test to assess tumor sensitivity to Rick Simpson Oil, a high-potency MC product marketed with an antineoplastic claim. However, even when participants reported meticulous documentation or adhered to a Rick Simpson Oil protocol, few participants had more than rough estimates for daily consumed dosages (descriptions ranged from "about a grain of rice" to about "50 mg in the morning" to "no idea" to a "a few puffs"). Many participants reported switching products from one dispensary visit to the next according to what was most affordable or featured by the dispensary.

Theme 4: Patients Relied on Nonmedical and Anecdotal Sources for MC Information

Nearly all participants cited the cannabis industry as a key source of MC information (n=21). Industry guidance covered appropriate cannabis indications, optimal strains, ratios and potencies of active ingredients, routes of administration, dosages, and titration strategies. Modes of education included one-on-one interactions with dispensary staff, public addresses (eg, at local libraries), and print and online materials (eg, YouTube videos).

Friends and loved ones often provided general encouragement and a wide range of information regarding MC (n = 14). Their advice to use MC was the most commonly cited reason for participants to initiate use. In addition, friends and loved ones recommended health care professionals who could issue certifications as well as educational movies and articles on the subject.

Theme 5: Patients With Cancer Used MC for Multipurpose Symptom Management and as Cancer-Directed Therapy

Participants reported using MC for the management of symptoms, including pain (n = 19), nausea/poor appetite (n = 14), anxiety/depression (n = 13), and poor sleep (n = 10). Other indications included attention-deficit disorder, fibromyalgia, gastrointestinal distress, muscle spasm, and posttraumatic stress disorder. A few sought cannabis-induced euphoria. Often, participants used MC for multiple indications. For example, a patient used it for "nausea, pain management, and then anxiety."

Beyond symptom management, more than half of the sample reported use of MC to treat the cancer itself. These individuals frequently reported a belief that MC possesses anti-inflammatory, apoptotic, and tumor-suppressive effects. Eight of those using MC to treat cancer reported using Rick Simpson Oil. Three used Rick Simpson Oil instead of standard cancer-directed therapies, even though the latter were available to them. Among those using MC for cancer treatment, 8 were hopeful about MC's efficacy (eg, "I can't say I really think it's the beall and end-all of ... cancer treatment"), whereas other strongly believed in its antineoplastic properties (eg, "I had watched a documentary about cannabis and cancer, and I made a decision right then and there I wasn't going to touch chemo").

DISCUSSION

In this qualitative study of patients with cancer using MC, we found that the majority of participants received MC certifications from medical professionals outside their established medical teams. Consultations with these clinicians were typically brief and transactional. It was often the responsibility of patients to communicate MC use with the rest of their care providers. By contrast, a few of the patients that we interviewed reported having received MM certifications from a primary care provider, oncologist, or other specialist. In these cases, visits included physical examinations and more extensive discussions of MC's risks and benefits, as intended under the

law. Notably, several patients reported using MC because of its purported antineoplastic properties, sometimes in lieu of chemotherapy or other treatments considered to be standard of care within oncology.

Every patient that we interviewed sought advice from their established medical teams about MC. Despite this, few providers seemed prepared to discuss the topic. Many patients reported that their providers were either unwilling or unable to offer advice about MC even though they responded neutrally to the news that patients were using this agent. Although this study was not designed to explore why this might be the case, one could imagine several potential factors, including MC's federally illegal status, the stigma that surrounds the agent, its immature evidence base, and limited access to MCrelated continuing medical education. 20,21 Unfortunately, without guidance from either their established medical providers or MC certifiers, most patients reported relying on nonmedical sources—specifically, the cannabis industry, word of mouth, and internet searches—to learn about indications for MC, active ingredients, routes of administration, dosing, and risks and benefits.

This study has several limitations. First, we relied on a convenience sample, which was vulnerable to a selection bias. Second, the representation of Asians, Hispanics, and African Americans in the sample was small, so our data likely did not fully capture the views of these groups. Future studies should enrich their samples for ethnic diversity to learn whether our findings are translatable. Third, our conclusions are not generalizable to noncancer populations. Even in the face of these limitations, however, our study included a broad representation of patients of different ages, cancer stages, and geographic regions, and each had a state-based MC certification and a cancer diagnosis that was verified by a physician. We believe that our formative qualitative data describing previously unknown mechanisms by which patients access MC-related products, information, and know-how remain an important addition to the scientific literature.

Although the medical community's approach to MC might not differ substantially from its approach to other complementary and alternative medicine therapies, MC is distinct from other such products (eg, curcumin or echinacea) in that it has been exceptionalized by MC laws, which mandate health care professionals to guide care in this domain. Our preliminary findings, stark and relatively consistent across participants, have important clinical and research implications. The study findings suggest that, in a climate of increasing cannabis legalization and a growing MC industry, medical providers who wish to best

meet their patients' needs should familiarize themselves with the existing data for MC—and its limitations—to guide care in this domain. Taken in the context of the national survey of oncologists, the study conclusions also invite medical practice organizations and national professional societies to generate continuing medical education materials for health care professionals and to develop clinical practice guidelines for MC. Such actions on the part of medical providers and organizations may enable primary medical teams to assume greater oversight for MC-related decision making and safety monitoring and ostensibly ensure that MC programs are operationalized within an evidence-based framework.

In conclusion, semistructured interviews with a geographically diverse sample of patients with cancer using MC (n = 24) suggested a significant lack of integration of MC into medical care. MC certifiers and medical teams offered startlingly little clinical guidance regarding MC. Given these gaps in care, patients with cancer were reliant on low-quality, anecdotal, or commercial resources for MC information. Notably, oncology patients reported using MC for symptom management and as cancer-directed therapy, sometimes instead of traditional treatments. These findings highlight important future directions for MC-related research and clinical care.

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Peter R. Chai reports grants from Gilead Sciences and E Ink Corporation outside the submitted work. Miryam Yusufov reports personal fees from Blue Note Therapeutics outside the submitted work. The other authors made no disclosures.

AUTHOR CONTRIBUTIONS

Ilana M. Braun: Conceptualization, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, resources, supervision, validation, visualization, writing—original draft, and writing—review and editing. Manan M. Nayak: Conceptualization, data curation, formal analysis, investigation, methodology, project administration, resources, software, supervision, validation, visualization, writing—original draft, and writing—review and editing. Anna Revette: Conceptualization, data curation, formal analysis, methodology, resources, and software. Alexi A. Wright: Data curation, writing—original draft, and writing—review and editing. Peter R. Chai: Data curation, writing—original draft, and writing—review and editing. Miryam Yusufov: Data curation, writing—original draft, and writing—review and editing. William Pirl: Data curation, writing—original draft, and writing—review and editing. James A. Tulsky:

Conceptualization, data curation, formal analysis, funding acquisition, methodology, resources, supervision, writing—original draft, and writing—review and editing.

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