‘Somebody checking-in’: a qualitative study to develop a patient-centered digital healthcare technology for young adults in opioid use disorder treatment

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Abstract

Background: Young adults drop out of opioid use disorder treatment more often than older adults. Premature treatment drop-out substantially increases fatal overdose risk. Digital healthcare applications integrated within treatment can potentially engage young adults to self-monitor for drop-out risk factors.

Objective: This pilot proof-of-concept study examined the feasibility, acceptability, and utility of a patient-centered digital healthcare technology, AWARE (Awareness and Response to the Environment), designed to bring attention to treatment drop-out risk factors.

Methods: In this formative research, a convenience sample of young adults (n=3) in methadone treatment, their counselors (n=3), and clinic leadership (n=2) were recruited from an opioid treatment program and interviewed to obtain feedback as AWARE was developed. In 8 semi-structured interviews, perspectives regarding barriers to treatment for young adults and AWARE utility were obtained. Concurrently, three dyads of young adults (n=3) and counselors (n=3) piloted the intervention daily for 4 weeks.

Results: Young adults and counselors found AWARE relevant to their treatment experience and acceptable to complete over 4 weeks. The most frequently reported daily stressors were ‘the health and well-being of a family member,’ ‘being organized,’ and ‘having too many things to do without help.’ In qualitative interviews, counselors and clinic leadership reported that AWARE presented a relevant, new way to engage young adults daily, in addition to weekly counseling sessions. Young adults felt that AWARE offered a type of social support they lacked, like ‘someone checking in on them’.

Conclusions: Overall, young adult and counselor participants were able to engage in AWARE in a busy clinic environment, and participants and clinic leadership found it valuable. Further research is needed to refine the measures and methods of AWARE and evaluate its effectiveness. Clinical Trial: N/A

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This study was approved by WCG IRB and the City of Philadelphia IRB.
Consent to participate
Informed written consent was obtained from all young adult participants in the study. Informed verbal consent was obtained from all treatment providers.
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The authors obtain permission to publish from the City of Philadelphia.

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Conclusions: Overall, young adult and counselor participants were able to engage in AWARE in a busy clinic environment, and participants and clinic leadership found it valuable. Further research is needed to refine the measures and methods of AWARE and evaluate its effectiveness.

Keywords: *ecological momentary assessment, treatment barriers, opioid use disorder, young adults, opioid treatment programs*

Introduction

Young adults, ages 18-29, have the highest opioid use rate per capita.[1] Despite the efficacy of medications (e.g. methadone, buprenorphine) to prevent morbidity and mortality related to opioid use, young adults with opioid use disorder (YAOUD) are less likely to initiate treatment[2,3] and more likely to drop out of treatment[4] compared to older age groups. A personalized behavioral treatment responsive to the individual needs of young adults may increase retention by addressing coping skills associated with YAOUD's stressors and thoughts of leaving treatment.[5-8]

Addressing Risk Factors through Ecological Momentary Assessment

The scientific understanding of risk assessment in a real-world context has been advanced by ecological momentary assessment (EMA) research methods.[10,11] EMA is a data collection technique

requiring frequent self-monitoring of symptoms, thoughts, and social interactions, enabling the identification of unfolding patterns of mental states and behavior.[12] Self-monitoring through text messaging (an EMA method) has been used extensively among people with OUD to identify treatment drop-out risk factors through pattern recognition.[13-18]

People with opioid use disorder (OUD) have differing retention trajectories based on levels of stress.[19,20] The variability of stress, not the averages at points in time, best predicts craving and future opioid use.[21] According to self-management and cognitive relapse prevention theories, greater attention to and awareness of mental states may lead to improvements.[22,23] Drop-out risk factors like stress may normally be unconscious to a person, but self-monitoring can bring them to the forefront and, thus, increase the opportunity for the patient and counselor to develop more specific plans, coping strategies, and more control.[24] It is likely that automatic responses to stress, when brought to cognitive awareness, become easier to address and extinguish.[25]

Prior research has incorporated EMA data within OUD treatment to engage participants through text messages to remind participants of appointments[26], mHealth applications to deliver therapy[27-29], and web-based software to access and deliver cognitive behavioral therapy.[30] However, few digital interventions are described in the literature that incorporate EMA data into counseling sessions within an existing opioid treatment program (OTP). Integrating real-time patient-generated data at the point-of-care has the potential for significant impact by informing risk assessment and augmenting existing treatment.

Study Purpose

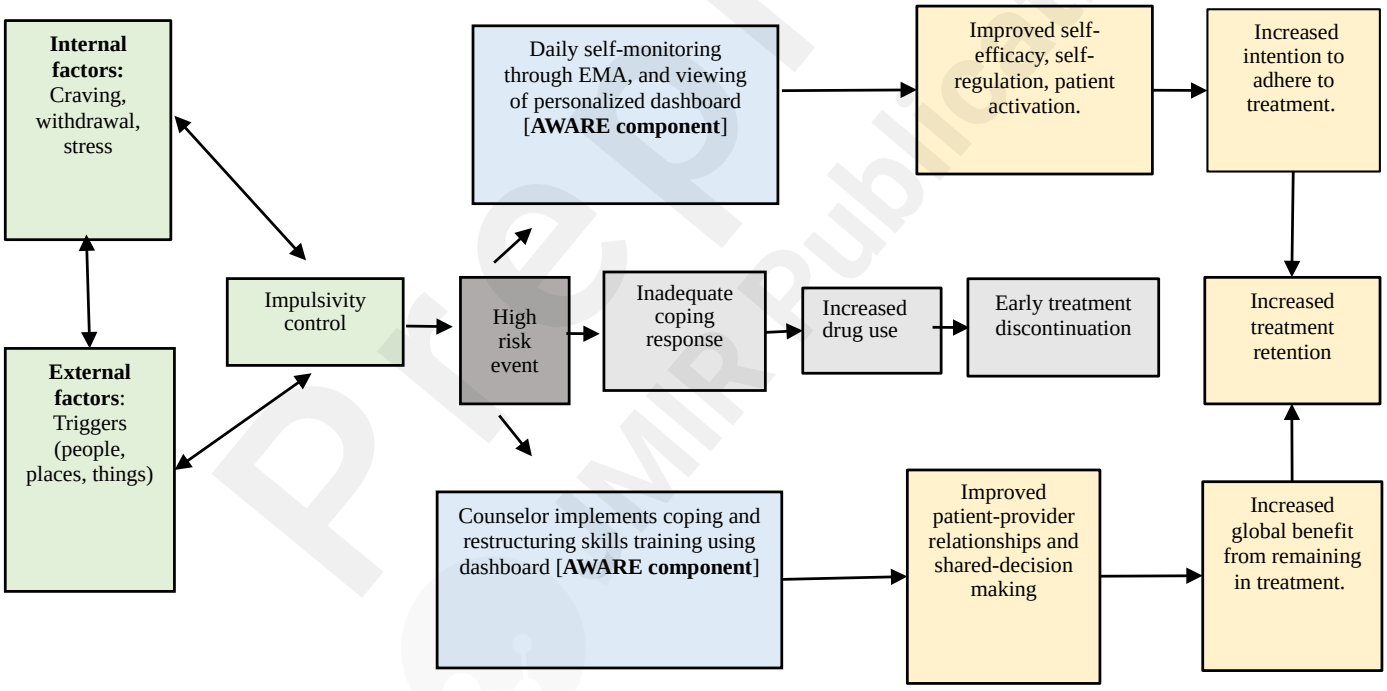
The present study developed and pilot-tested an intervention tailored for YAOUD called "AWAreness and Response to the Environment (AWARE)." AWARE used REDCap software to send EMA surveys on a study-provided phone, collecting patient-generated data on antecedents of treatment drop-out that could be integrated into weekly counseling sessions. The purpose of this paper is to 1) describe the use of AWARE by YAOUD and treatment staff, 2) detail the perceived

barriers and facilitators of treatment engagement, and 3) describe how AWARE may address identified barriers. This pilot, proof-of-concept project will lay the foundation for a future clinical trial of AWARE.

Theoretical Framework

The conceptual framework for AWARE draws from self-management and cognitive-behavioral relapse prevention theories, which are applied to the *retention* stage of the OUD Cascade of Care.[31] To target improvements in the retention stage, self-efficacy beliefs ("*I'm going to the clinic today*") and adherence ("*I received medication today*") to medication are crucial.[32,33] Interventions underpinned by self-management theory in HIV and substance use research have shown success in

Figure 1. Integration of Cognitive Behavioral Relapse Prevention and Self-Management Theories



increasing medication receipt and adherence.[34,35] Self-management theory emphasizes that improvements in self-efficacy beliefs can result in better decision-making and intention to adhere to healthy behaviors.[34-36] Cognitive-behavioral relapse prevention theory demonstrates that relapse (defined as a setback in progressing towards recovery) is not a binary event but, rather, a dynamic, fluctuating process (see **Figure 1**).[26,7] The rationale for integrating these two theories stems from the

utility of self-management-based interventions in chronic disease and the chronic, relapsing nature of addiction.[35,37] Improved self-management skills for someone with OUD may prevent future relapses but also could improve daily cravings, negative mood, and stress, which may reflect a greater benefit to an individual than abstinence from drugs alone.[38] These personal benefits may also positively reinforce treatment adherence thereby making the work of recovery more appealing to participants.[39]

Methods

Setting and Design

YAOUD and treatment staff recruitment took place at an urban, Northeastern United States OTP that offers methadone or buprenorphine and individual and group counseling informed by Cognitive Behavioral Therapy (CBT), using the NIDA CBT manual.[40] Each incoming patient receives an individual counselor with a caseload of 25-30 patients. The program does not currently use patient-centered digital healthcare technology. Medications administered and dispensed, as well as doses and drug screening results, are recorded in an electronic health record (EHR). Urine samples are obtained randomly at least twice per month, and patients are not discharged for drug use alone. Rather, continued opioid or other drug use may impact clinical decisions regarding take-home medication, dosage, and counseling approaches. Reasons for discharge are noted in the EHR. During our pilot study, we capitalized on already existing resources, including existing counselors, to adapt AWARE into the opioid treatment center structure. This study used a qualitative approach, which is appropriate for formative work. The study was approved by both WCG IRB and the [Blinded] IRB.

Table 1. AWARE intervention integration of EMA data into counseling sessions

Participation and Roles of Participant and Counselor	Activities	Theoretical Construct
Participant (Daily) ➢ Self-monitors via EMA ➢ Views dashboard ➢ Real-world practice of skills	➢ Identifies and examines thoughts, symptoms, triggers of drop-out ➢ Practices coping skills ➢ Practices problem solving	➢ Self-efficacy, self-regulation, patient activation ➢ Coping, relapse/drop-out prevention ➢ Self-efficacy, relapse prevention
Study Counselor (Weekly) ➢ Views dashboard ➢ Analyzes patterns	➢ Identifies and examines thoughts, symptoms, triggers of drop-out ➢ Identifies contextual issues affecting intention to stay in treatment	➢ Self-efficacy, self-regulation ➢ Self-efficacy, self-regulation

	➢ Teaches and leads rehearsal of coping skills (emotional and trigger coping) ➢ Engages in problem solving	➢ Coping, relapse/drop-out prevention ➢ Coping, relapse/drop-out prevention

AWARE intervention

AWARE was developed as a self-monitoring, mobile phone-based intervention that couples EMA surveys with counselor feedback during weekly CBT sessions. The goal of AWARE is to augment standard care, which includes medication, through identifying and responding to high-risk events or situations known to predict drop-out. The EMA structure, content, and timing in this project are informed by longitudinal studies that sought to predict early treatment drop-out using EMA.[19,41-47] For this pilot study, the Daily Hassles Survey[19], a list of external stressors, was used to identify stressors particular to YAOUD. Weekly data summaries were provided to the participant and their counselor via email (see **Table 1**).

Eligibility Criteria

The study recruited YAOUD who were (a) ages 18-29, (b) receiving counseling during OUD treatment, and (c) English speaking. We excluded YAOUD if they exhibited (a) active suicidal ideation and/or (b) active psychosis. Inclusion criteria for treatment provider/staff interviews included a) counselors with a client enrolled in AWARE or b) clinic leadership.

Recruitment and Screening Procedures

The research assistant approached eligible YAOUD participants during dosing, asking them if they would like to participate in a study regarding a mobile phone-based intervention. The research assistant then obtained written informed consent and conducted the baseline interview. Participants were then oriented to the EMA survey procedures. Treatment center staff were recruited at a kick-off breakfast event at the treatment center. Staff provided verbal consent to the interviews before their interview began.

Measures

All study participants completed a brief demographic questionnaire at baseline. In addition,

YAOUD participants completed the daily stressors questionnaire. Qualitative interviews were performed using a semi-structured guide before and after AWARE implementation. All participants were asked key questions regarding perceived barriers to treatment for YAOUD and the utility of AWARE in improving treatment engagement. Suggestions for improvement, as well as content or delivery methods, were obtained. Participants received a $50 gift card upon completion of the qualitative interview. YAOUD participants were paid $50 in cash at the beginning and end of the AWARE intervention, and they also received a study phone if desired.

Data Analysis

Interview data was analyzed using thematic analysis methods: generating initial codes, searching, reviewing, defining, and naming subthemes, and identifying basic and global themes. Transcripts were reviewed independently by a master's prepared research assistant and a PhD prepared investigator using rigorous and accelerated qualitative data reduction (RADaR) and content analysis.[48] A series of spreadsheets was created to produce short, concise data tables. From discussion of these tables, consensus was reached on the content and relevance of themes identified. The identified daily stressors were tabulated using frequency of identification and ranked from most identified to least identified.

Results

Of the 14 young adult clients at the opioid treatment program, 8 were contacted and the research team never received a response, 3 were discharged from the treatment center before contact could be made, and 3 were successfully enrolled. The 3 consented YAOUD participants (67% female, 67% Latino/a) were sent daily surveys for 28 days (53% overall completion rate), and only two YAOUD participants finished the study. All three counselors received a weekly data summary. YAOUD and counselor ratings of the usability of the platform were favorable; all agreed with statements that the daily surveys were clinically useful, easy to navigate and relevant to the treatment experience. The YAOUD and treatment center staff interviews centered on the previously identified

themes of treatment engagement stressors and barriers and the feasibility and usability of AWARE to promote treatment engagement.

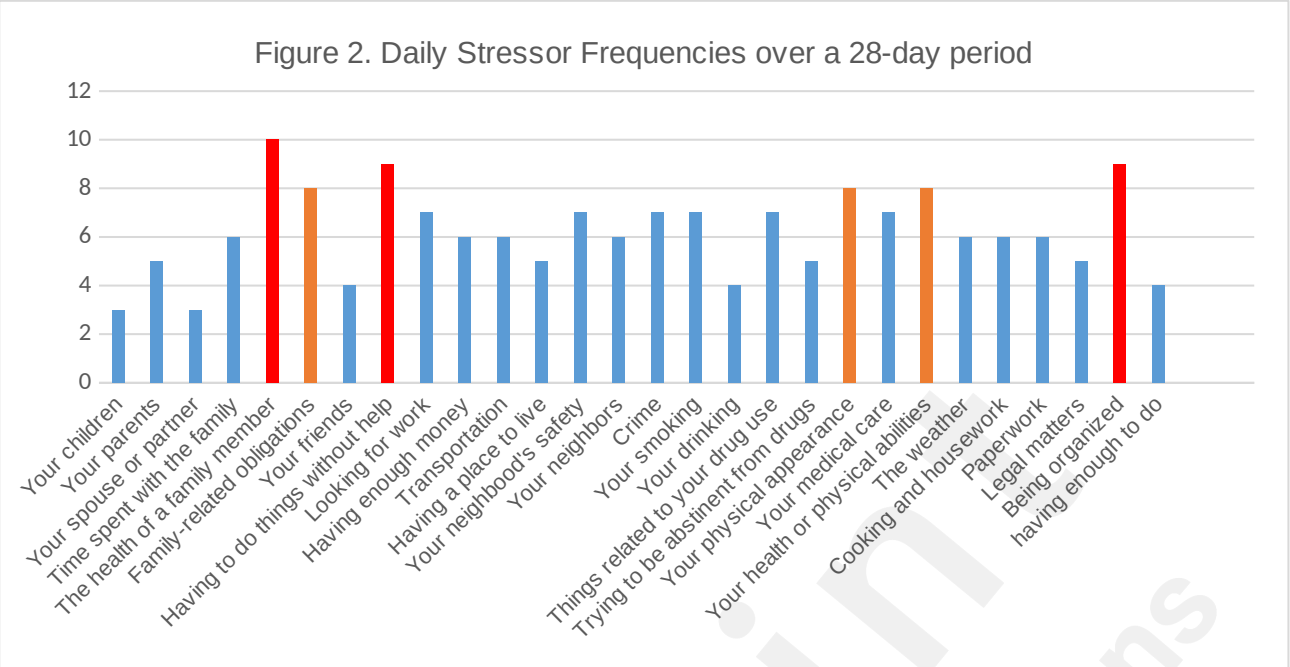
Participant Characteristics

Three YAOUD participants consented to participate in the study. The first participant was a Latina woman, age 27, living in her own home with her partner and child. The second participant was a Latino man living in a family member's house. The third participant was a Black woman experiencing ongoing homelessness; however, she was lost to follow up after responding to one week of surveys. All participants received a study phone to complete the AWARE surveys.

Five treatment center staff were recruited. All but one of the counselors had less than six years' experience as a drug and alcohol counselor. One clinic administrator had over twenty years of experience working in therapy within opioid treatment programs. Two treatment center staff identified as Black, one identified as Asian, and two identified as White. Treatment center staff interviewed primarily identified as women, except for one man.

Treatment Engagement Stressors and Barriers for Young Adults

YAOUD participants identified several stressors on daily surveys that may interfere with treatment engagement including 'housing', 'transportation', 'things related to drug use', and 'family obligations' (See **Figure 2**). In qualitative interviews, two YAOUD participants identified 'not having much to do' and not having any social connections outside of the clinic as a frequent stressor. The most frequently reported daily stressors were identified as 'the health and well-being of a family member', 'being organized', and 'having too many things to do without help'.



One participant described the care she provides daily for her child and her partner, who works night shift and also is a patient at the methadone clinic.

> I have to be up and ready by 7:30 am. [My partner is] outside and then I know we're coming to the clinic and he's tired, so he has to go home and sleep till he goes to work. So it's like I know I can't do nothing Monday through Friday but cater to him and the baby. (Participant 1)

Each YAOUD reported in their interviews that they had difficulty in the past with clinic regulations and the clinic environment. This was not the first treatment episode for any YAOUD participants. The social environment around the clinic was not seen as positive. Most participants reported going to and from the clinic and not spending time with peers.

> Well, it's like with this time, this isn't my first rodeo, so I know what to do this time. So I know this might not be the best answer, but this works for me. I isolate and it's not good. I isolate because I don't live in a nice neighborhood. There's drugs everywhere, but I don't like, it's definitely my mindset. I just go straight home and I try to keep a one track mind, but I mean, that wasn't good for me to do it back then. (Participant 3)

YAOUD participants also reported they did not have much to do and making money at a job posed a problem, as they feared they may use the money for drugs.

> Because you got to understand the last 10 years of my life getting high was my hobby, my interest. So when I just stop, you do feel lost, then that's when depression and being miserable, that all kicks in. You just don't know what to do. But I just got to find new shit to do, to keep me occupied, and I don't even know what to do right now. You know what I mean? It's weird. I feel like I'm learning myself. I feel like how I felt when I was in high school. I am learning, trying to find myself, [trying to find things] that interest me instead of getting high. (Participant 3)

Treatment center staff had a similar perspective to YAOUDs regarding stressors and barriers to treatment engagement. All five treatment staff participants mentioned housing as a distinct barrier

to stay in treatment. However, treatment center staff also highlighted issues related to childhood trauma, motivation, and family disconnection as barriers to maintaining recovery.

> A lot of [clients] are not close with their families anymore, so I mean they don't have anything to look forward to. Holidays, everything is just a regular day to them, so because they don't have the motivation or the push, it makes it very difficult to keep them engaged on sobriety. They don't see a reason to be sober. (Staff 2)

Difficulties staying away from drug use was linked by several treatment center staff to the environment in which participants lived and socialized. According to treatment center staff, there was little motivation to stay away from drugs and stay in treatment was lacking for many participants, due to a lack of positive relationships. Treatment staff also mentioned that the relationships that they do have at the treatment center are not always positive and that many times staying away from people is a strategy young adults employ in order to stay engaged in treatment.

AWARE Feasibility, Acceptability and Usability

Young adults and treatment center staff found AWARE to be relevant, acceptable, and feasible to complete over 4 weeks, although completion rates varied. Of the three YAOUD participants who began the AWARE intervention, only two completed over 90% of the 28 surveys sent. The third participant completed less than half of the surveys sent. Participants reported that it took 5-10 minutes to complete their daily survey and that AWARE was “easy to use” and “didn’t take much time”.

> I think it pretty much everything made sense the way [AWARE] was set up because there wasn't too little questions or too much. It was kind of perfect to just reflect or more or less. (Participant 1)

YAOUD participants felt that AWARE was offering a type of social support, like “someone checking in on them”. One participant mentioned they were able to keep in contact with their parole officer as a result of having a study phone.

Clinic leadership and counselors reported that they felt AWARE presented a relevant, new way to engage young adults on a daily basis, in addition to weekly meetings. They also mentioned that AWARE allowed for anonymous reflection on the part of their clients. Counselors also appreciated that AWARE enabled weekly discussion of stressors based on patient-generated, real-

time data.

> [You] sent me a summary of my client's information, and I thought that was really helpful. I can actually bring this up in session and see what exactly going on. Because usually in session, it's kind of hard to pull that out of him or it's the generic, ‘how are you doing’, ‘how’s your week been’, and ‘it's fine, fine’. (Staff 4)

Treatment center staff also identified AWARE as an intervention that provides check-ins with their clients, addressing the scarcity of relationships in their clients’ lives. AWARE extended the reach of a positive relationship at the treatment center through automated messaging and required response.

> And I think it's great because it's daily, because in a way it gives them something to feel a part of. Like somebody cares, there's a regular check-in. A lot of them don't have anything, don't have anybody asking them anything. Don't have any conversations, nobody checking in. (Staff, 2)

Discussion

This is the first study to develop a patient-centered digital healthcare technology specifically for young adults in OUD treatment to promote retention through client-counselor engagement with EMA data. Initial findings from this pilot project indicate that delivery of daily surveys to young adult participants and the delivery of weekly summaries to counselors regarding stressors is not only possible, but relevant to all involved. Prior research has found that people in OUD want a more personalized approach to treatment.[49] AWARE was able to reach out to participants on a daily basis and make them feel supported, and less alone.

YAOUD participants identified several stressors that may interfere with treatment engagement including housing, transportation, drug use, and family obligations. Two YAOUD participants identified ‘not having much to do’ and not having any social connections outside of the clinic as frequent stressors. Among individuals with opioid use disorder (OUD), loneliness has been recognized as a factor that drives substance use and increases cravings, and it is linked to significant triggers that can lead to relapse.[50] Higher levels of loneliness are associated with positive urine drug screens among people in OUD treatment at the six-month follow-up.[51] It is possible that more contacts with positive relationships, through an intervention similar to AWARE, could not only

increase treatment engagement, but begin to address social isolation.

Interventions that integrate a response to patient-generated data within existing substance use disorder treatment are more effective than self-monitoring alone at improving treatment retention.[52] However, patient-generated data has not been integrated within a direct point-of-care system workflow to inform treatment response to address drop-out risk factors at an opioid treatment center. AWARE presents an opportunity to integrate real-time patient-generated data at the point-of-care has the potential for significant impact by informing risk assessment and increasing opportunities for patient engagement and shared decision-making regarding treatment options. Such an approach promises to increase early treatment retention and thereby improve the quality of care and reduce the risk of overdose death.

Limitations

All participants received the intervention. Future studies will be trials of AWARE and will include control and intervention groups to test the effect of AWARE. The small sample size of this specific study tested the recruitment strategy and highlighted the small number of young adults in treatment for OUD at a large, urban opioid treatment center at one point in time. However, our sample size was sufficient for obtaining qualitative feedback on the feasibility and acceptability of a newly developed technology.

Conclusion

Overall, YAOUD and treatment staff participants were able to engage in AWARE in a busy OTP environment, and participants found it valuable. Further research is needed to refine the measures and methods of AWARE and evaluate its effectiveness.

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