Assessing mobile health feasibility and acceptability among HIV-infected cocaine users and their healthcare providers: guidance for implementing an intervention

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Background: Mobile health (mHealth) can provide innovative, cost-effective strategies to improve medication adherence and optimize HIV treatment outcomes. Very little, however, is known about the acceptability and feasibility of mHealth among people with HIV (PWH) who use drugs. Our study objective was to assess feasibility, acceptability, and barriers and facilitators of implementing an mHealth intervention among PWH who are cocaine users, a group for whom no pharmacological treatment to reduce cocaine use is available.

Methods: Five focus groups (FGs) (N=20) were conducted with PWH who self-reported cocaine use in the past 30 days, with 3 groups (N=8) of healthcare providers. Topics included previous experience with smartphones; barriers and facilitators of mobile technology for health purposes; and attitudes toward receiving types of feedback about adherence.

Results: Patients preferred text reminders over phone calls for reasons of privacy, accessibility and economizing phone minutes. Direct communication via text messages and phone calls was considered more appropriate for social workers and case managers, who have greater frequency of communication and deeper relationships with patients, and less so for doctors, who see patients less regularly than community health workers. Patients seem particular about who has what information, and overall, they seem to prefer that their medical information, especially HIV-related, stay within the confines of patient-provider relationships.

Conclusions: HIV still provokes stigma and makes health information particularly sensitive for both providers and patients. The rise of mobile technology and related applications such as mHealth, means that new norms have to be established for its use. Participants' suggestions and feedback informed the design of a subsequent mHealth pilot randomized control trial to improve medication adherence.

Keywords: Mobile health (mHealth); HIV; focus groups (FGs); feedback; cocaine

Introduction

For people with HIV (PWH), viral suppression remains an important health goal, one that can be achieved by adhering to HIV medication, namely antiretroviral therapy (ART). Benefits of adherence to ART include reduction of risk of transmission to others, decreased morbidity and mortality, and reduced emergency department visits and hospitalizations (1,2). Maintained effectiveness of ART depends highly on the patient's persistence and ability to adhere to their medication regimen (3-6). Substance use disorders can exacerbate health outcomes by reducing ART adherence and persistence (7-9). The high prevalence of cocaine use among PWH is particularly problematic as cocaine is not amenable to pharmacological interventions (10-13). Though directly-administered ART is an evidence-based intervention that does work in this population (14-16), it is expensive, labor-intensive, seldom available, and out of step with current recommendations for interventions to be more cost-effective and less burdensome on patients and providers (17).

Mobile health (mHealth), the use of mobile and wireless devices in healthcare, represents an opportunity to deliver innovative, efficacious and cost-effective strategies to improve ART adherence and optimize HIV treatment outcomes (18,19). Exploring feasibility of mHealth among PWH is consistent with international guidelines that identify an urgent need for innovative yet cost- and labor-efficient interventions (17). mHealth tools can not only monitor medication adherence in real-time (e.g., cellular-enabled smart pillboxes) (20,21), but can also be used to promote adherence in temporal proximity to actual medication intake through automated reminders and interactive communication (22-26). Mobile text messaging has already been shown to increase treatment adherence and retention in care among patients with chronic conditions such as diabetes, tuberculosis, malaria, asthma and HIV (24,27-31).

mHealth has been identified as an important potential facilitator of improving retention in HIV care and adherence to ART (32,33). Of the uses of mHealth for HIV prevention and treatment, its use to promote adherence has the strongest evidence base (34). mHealth in weekly intervals has been shown to be effective in enhancing adherence to ART compared to standard care (35). A growing number of interventions use communication via text-messaging to improve antiretroviral medication adherence (36). mHealth tools and interventions have been scantily examined in underserved HIV populations such as prisoners, men who have sex with men, and those with substance use disorders among others (34). These groups of PWH have historically faced greater social stigma and healthcare discrimination, making them especially vulnerable (37). A meta-analysis of 11 studies found that scheduled reminders significantly increased ART adherence, yet none of the studies were conducted with patients with substance use disorders (38).

Given the ubiquity of mobile technologies and promising results that can be seen from the burgeoning field of mHealth, Krishnan and Cravero (39) point out that underserved PWH can benefit from "evidence-based innovations that could mitigate their vulnerabilities". Although mHealth tools for PWH have been developed for those who use tobacco (40) and methamphetamine (41), mHealth tools have never been developed or tested in PWH who use cocaine, a particularly underserved cohort. Furthermore, when mHealth interventions are implemented, they are often done without input from healthcare providers. To fill this void, the present study aims to assess the feasibility, acceptability, and barriers and facilitators of mobile technology and mHealth interventions among PWH who are cocaine users and their healthcare providers. mHealth experts recommend formative research as the most important step in developing mHealth interventions to design "culturally sensitive interventions which truly understand the audience" (42). For underserved HIV populations, a multipronged evidence-based approach has been suggested that involves assessing mHealth feasibility and accessibility through descriptive studies, conducting pilot projects testing mHealth tools, and integrating mHealth tools into existing large-scale studies (39).

Theoretical perspective to inform mHealth acceptability and feasibility

In their systematic review of mHealth use in low-resource environments, Chib *et al.* (43) identified a lack of theoretically-grounded studies, which is integral to measurable health outcomes and future evidence-based policy decision-making. Our formative research utilized the theory of technology acceptance model (TAM) to examine mobile technology usage patterns and acceptability of mHealth to establish support for a large-scale mHealth intervention. The TAM introduced by Davis (44) posits that people accept the use of information and communication technologies primarily because of key features of the technology in question, specifically perceived usefulness and

perceived ease of use. Perceived usefulness is defined as "the degree to which a person believes that using a particular system would enhance his or her job performance" and perceived ease of use as "the degree to which a person believes that using a particular system would be free of effort" (44). Although the TAM was initially developed to understand the acceptability of new systems within information technology organizations, this theoretical model has been widely utilized to understand and predict the acceptability of various technologies by different user groups in diverse contexts. For example, TAM has been extensively used to understand acceptability of health information technologies (45-48).

So far, only a few studies have examined end-user acceptability of technology in the context of HIV and substance use disorders (49-51). Genz *et al.* (51) surveyed current and former injection drug users and lower reported use of technology was identified as a potential barrier to successful implementation of mHealth and Internet-based interventions. Schnall *et al.* (50) used TAM and e-commerce acceptance model as theoretical frameworks for their focus groups (FG) and found that PWH perceived mHealth to be useful and easy to use, and had trust with technology and low concerns with privacy. In keeping with these studies, we incorporated elements of TAM in designing the questions in the FG guides. The context of our study—PWH who use cocaine and their healthcare providers, and the methodology utilized—qualitative focus groups, demonstrates a new direction for the TAM.

Methods

Study approach and FG guide development

Qualitative research has been increasingly employed in health contexts since the 1990s (52,53) and can be particularly beneficial for feasibility studies (54). As a research method, FGs are useful for uncovering beliefs about a specific topic and descriptions of and explanations for normative behavior (55,56). We were interested in comparing beliefs and behaviors of two groups with different expertise: patients and providers. We incorporated TAM elements into the FGs with perceived usefulness represented by questions about knowledge about communication technology and perceived ease of use by asking questions about behavioral skills.

Two FG guides were developed with the following topics in common: (I) previous experience with communication

technology; (II) barriers and facilitators of mobile technology for health purposes; (III) attitudes toward using mHealth tools for health maintenance; (IV) acceptance of mobile technology and mHealth tools; (V) attitudes towards sending/receiving different types of feedback about adherence behaviors; (VI) content and nature of feedback most likely to improve adherence. Providers were asked to describe patients' barriers to technology, but patients were not asked about providers' barriers or comfort with technology. Providers were asked about technology use in their workplaces. Patients were asked more questions than providers about preferred reminders and trust in technology, healthcare providers, and family and friends. A systematic review found a lack of definitive data about the effectiveness of electronic reminder devices, including text messages, to improve ART adherence (57). Hence, we also asked participants if an electronic pillbox that sent reminders as text messages to their phones would help them take their antiretroviral medication on time.

Data collection procedure

Eight FGs were conducted between November 2016 and February 2017, five (N=20) among cocaine users with HIV (referred henceforth as patients) and three (N=8) among healthcare providers. A moderator trained in qualitative research conducted FGs in a research office with a note-taker to improve and correct the audio transcriptions. Eligible patients were at least 18 years of age, self-reported HIV+ status and cocaine use in the past 30 days, able to speak English, and able to provide informed consent. Eligible healthcare providers were able to speak English and give informed consent, and were currently employed as community-based HIV physicians, healthcare workers, clinic supervisors or substance use counselors. Patient recruitment occurred through flyers and word-of-mouth at HIV and drug treatment clinics, a mobile medical unit, and support groups in the city. Provider recruitment was initiated through flyers and emails sent to the members of New England AIDS Education and Training Center. Participants received a $25 gift card for their participation. We did not collect participants' demographic information to maintain privacy and confidentiality.

Analysis

All FGs were audio-recorded and transcribed, checked for accuracy, and analyzed through content analysis (58)

facilitated by the text analytical software NVivo® 10 (QSR International, Doncaster, Australia). A directed content analysis approach (59) was used to identify patterns and themes in the data based on the categories of interest. Content analysis is a well-established method for analyzing qualitative data and is widely employed across the social, behavioral, and biomedical sciences (58,60). Using this approach, the review of text as an iterative process reveals themes; some themes were derived directly from the FG guides, while other themes emerged from patterns in participants' responses. The study and FG guides were designed by SE Brown, A Krishnan, FL Altice. FGs were moderated by R Marcus and YS Ranjit and coded into themes and analyzed by SE Brown. Data synthesis involved all co-authors.

Ethical considerations

The study was approved by the Institutional Review Board at Yale School of Medicine. Verbal consent was obtained from all participants to ensure anonymity. Due to potential stigma faced by participants regarding their HIV status and self-reported cocaine use, patients were encouraged to use pseudonyms during the FGs.

Results

Major themes emerging from patient FGs were: patients' concerns about privacy, preferences about reminders, and views on an electronic pillbox for reminders. Major themes emerging from provider FGs were: workplace technological capability, providers' views on sending text messages to patients, and providers' concerns about patients' access to them. Providers and patients expressed high receptiveness to using communication technology, in its broadest sense, to improve patients' health. Patients' reasons for using phones included staying connected with their social network, receiving text reminders for appointments, information-seeking, and recreational use. Patients stated that they used phones and electronic medical record (EMR) portals to call and message medical providers. Because patients mostly depended on phones provided by the state and on pre-paid cards provided by community service organizations, they were vulnerable to inconsistent phone use, such as number changes, disconnections, and running out of pre-paid minutes before the end of the month. Providers in one FG (provider FG2) described outreach workers taking patients to their service provider to purchase more minutes for

them.

Patient-level factors

Concerns about privacy

Privacy and confidence in the electronic medical system were important themes among patients. Although mobile phones were considered useful, some patients reported limited computer use or expressed security concerns about the Internet (patient FG2) because of distrusting technology and worries that medical information, particularly their HIV status, could be hacked through their phone (patient FG2). With regard to HIV, patients wanted assurance that technology was secure because some patients already took great pains to make sure their HIV status was not disclosed to others. One patient said, "When I go to my Internet, I don't talk about my health or nothing with nobody" (patient FG2). Patients stated that they were living at shelters (patient FG2), rooming houses (patient FG3), warming centers (patient FG5) and apartments, either alone or with other people. One patient who did not want their children to know their HIV status explained, "As long as [the reminders] don't mention nothing about my HIV meds because of the kids in the house" (patient FG5). Not all of the patients worried about technology inadvertently disclosing their HIV status: "I know everybody want to be confidential. Now I got to the point where I worried about that before, now I don't care" (patient FG2).

Preferences about reminders

Patients stated that they liked receiving appointment reminders and check-ins as calls and texts from medical providers, mental health providers, and substance use counselors (Patient FG2). Some patients preferred calling to texting: "Calling is better… I will miss a text" (patient FG3). Another patient worried about missing texts because they put down the phone at home (Patient FG4).

One patient considered reminders "difficult. I tend to forget what I have to do. I forget the reminder to remind myself" (patient FG3). Facilitators of reminders to take medication included ubiquity and affordability of mobile phones (provider FG2). When asked how patients currently receive reminders, patients described strategies that comprised texting, phone calls, and physical actions. One patient described placing items next to clothes or in shoes that the person will wear (patient FG3). Patients expressed a desire to receive text reminders for taking medications and keeping medical appointments. One participant,

however, was concerned about becoming too dependent upon a phone for reminders: "What happens to you when your reminder is then misplaced, removed, or stolen? What happens then?" (patient FG3). A patient suggested wanting a phone call or text from a provider only about a day ahead of the appointment (patient FG1). Patients explained that the beginning and the end of the month would be the best times for reminders because it is more difficult to control drug use (patient FG2). One patient wanted the message to be discrete: "Keep it personal. Don't have to alarm it to the whole world and make it as personal to you as possible" (patient FG5).

Patients seemed mixed about receiving reminders from members of their social networks. One patient who described themselves as "a loner," living alone without a network of friends and family stated, "My responsibilities and my problems are my problems. Why burden someone else with my issues and concerns? They have their own life" (patient FG5). Another participant stated that some family members are uncomfortable with or ignorant of HIV, and therefore would not participate in sending reminder messages (patient FG5). Mothers seemed to be the only people who could be trusted with this information, but even after stating this, one participant said that they did not want to involve their mother in reminding them about medical appointments (patient FG5). One patient stated that because they speak openly about HIV, they would not mind if someone in their social network texted a reminder to them, but explained that they could not speak for everyone because not everyone is open about their status (patient FG4). Another patient in the same FG considered themselves to be self-reliant: "I don't really have any family that would remind me, just case managers and stuff like that, but I'm pretty good at reminding myself" (patient FG5). One patient who was diagnosed in 1986 said: "It's basically how we're living. We're taking care of ourselves, doing what we got to do" (patient FG5). One patient (patient FG4) stated that they were already receiving reminders from family members because of concerns about relapsing into drug use; this patient seemed less enthusiastic about receiving messages about appointments from people in their social network: "usually they just ask, Ma, don't you have an appointment coming up at so and so time or something like that but I don't care" (patient FG4).

Electronic pillboxes
We asked patients about the potential feasibility, advantages, and challenges of using an electronic pillbox that can give automatic instructional feedback or encouragement. One patient worried that an electronic pillbox would bring similar attention to their HIV in the same way that other pillboxes might: "I don't think [electronic pillbox] would be helpful for a lot of people because then they have to explain why they have to take all these meds" (patient FG2). Barriers to implementation of an electronic pillbox included the following: interruptions in patients' phone use (number changes, disconnections, running out of pre-paid minutes); transient life and abrupt changes to housing; providers' desire to maintain professional boundaries. For one patient, the pillbox would replace the need for reminders from family members like mothers (patient FG5).

Provider-level factors

Technological capability in the workplace
When providers were asked if they considered their workplaces to be tech-savvy, all the respondents stated that they would like to see their workplaces be more technologically oriented. Drawing comparisons between themselves and their workplaces, one provider said they were "very tech-savvy" but rated their workplace "moderately tech-savvy" because of new "bells and whistles" EMR portals, but wished that technology could facilitate more effective communication with patients (provider FG1). Elaborating further, this provider described expanding social media "to hook people up to HIV prevention messages or HIV prevention interventions," communicating with patients about appointments, and "interact(ing) with patients who have a need for certain services" (provider FG1). One provider described his organization printing new business cards for physicians with the email addresses removed because of a liability risk if a patient emails a provider about their care and receives no response (provider FG1).

Views on text-message communication with patients
Some providers liked texting their patients: "It's not just sitting face-to-face with them. (Texting is) a really easy way to contact you without having to do face-to-face" (provider FG3). Not all providers agreed, however. One provider stated, "I feel funky about sending a serum viral load to someone in a message" (provider FG3). One provider limited the uses for texting: "I only use (texting) for reminding people about messages or a clinical issue that needs to be addressed, but I don't remind them 'we talked about you doing this' and 'how are you doing' because that just opens the door for something that I might not be able

to address via text message" (provider FG3). Two providers believed that patients who are more stable or independent do not need phone calls (provider FG3). Providers worried for older patients who may not be tech-savvy (provider FG2).

Providers considered a text message from a case manager preferable to a text from a medical provider because of the higher frequency of communication and deeper relationships case managers and social workers have with their clients compared to medical providers (provider FG2). Providers believed that patients called case managers to solve or at least listen to non-medical problems, such as electricity shut-offs, etc. One provider believed that patient-provider face-to-face contact should not be completely replaced by technology because of non-verbal cues from patients during one-on-one meetings, which reveal patients' real health condition through eye contact, facial expressions and general appearance. One provider stated, "anybody can pull it together on the phone for a few minutes to try to convince you that life is grand" (provider FG2). Another provider suggested that doing more to match the patient by gender and culture might make it easier to identify someone whose personality will "click" with the patient's, thereby increasing the possibility of following the advice in the feedback (provider FG3).

Concerns about patients' access to them

Providers framed their ability to care for patients, including their communication with them, as needing to protect and manage their time. As one provider stated, "I don't have a problem seven days a week of making sure that my patient's needs are met if it's something that is going to improve their health outcome. Not everybody feels the same. Some people don't want their space intruded outside of working hours" (provider FG1). Providers worried about losing professional boundaries, such as early morning calls from a patient in crisis, non-urgent conversations (provider FG2), or "the risk of bad things happening" from maintaining an ongoing texting conversation with a patient (provider FG2).

Providers expressed positive attitudes toward EMR portals because of the ability to track messages sent to the patient, whereas a text message could end up "wherever" or "in limbo" and might not be received, or received by the wrong person (provider FG2). A third reason for a portal is that patient information is secure, so names and diagnoses can be in the messages (provider FG2). Absent from the discussion were specific concerns about compliance with Health Insurance Portability and Accountability Act (HIPAA) regulations.

Discussion

In this formative research of mHealth feasibility and acceptance among cocaine-using PWH, we found a high willingness to accept and use mobile technology to provide and receive care. Willingness does not equate to immediate uptake, as researchers found in a pilot study of mHealth use by healthcare workers (61), thus highlighting the importance of assessing mHealth feasibility and acceptability among PWH who are cocaine users and their healthcare providers. Patients and providers seem to accept mHealth's perceived usefulness, but perceived ease of use seems dependent on privacy concerns, integration of mHealth into existing adherence strategies for patients and for providers, technology infrastructure, and who will be the sender of the reminder text messages. The findings of this study disentangled patients' strategies and preferred messaging for medication adherence and receiving health messages.

Our current patient population includes people who either do or do not access the Internet, and those who use it for health information purposes. These findings might vary if our study had a different key population for HIV such as men who have sex with men who are known to be early-adopters of new technologies (62). Text messaging provides a sense of immediacy yet may provide the perception of increased access to their providers (63,64), which in turn may be beneficial for patients like our study population who report limited social support. Patients in this study may not have regular Internet access or be technically savvy to view medical information such as lab reports on an EMR portal, which is why two-way phone communication might be better for this population. In addition, EMR portals are currently not very portable and may not be easily accessed by mobile phone.

Privacy concerns

Concerns about data security remain a recurrent finding in literature on mHealth for PWH (50), yet was not discussed by providers. Fear of technology disclosing patients' HIV status is a finding consistent with that of Hall *et al.* (32) who found that fear of disclosure undermined retention in care and reluctance to utilize mHealth. HIV still provokes stigma and makes health information particularly sensitive for both providers and patients. Time since diagnosis may affect privacy concerns about disclosure. Newly-diagnosed patients may need time to come to terms with

disclosure, compared to those who had HIV for a longer period of time. Acceptance of HIV over time is consistent with the process of incorporating HIV into one's identity at specific points in time (65). For some, having HIV (or even a substance use disorder) can be isolating, and people may become self-reliant for medication adherence and life in general. In the case of cocaine use, for which there is no parallel medication-assisted treatment like there is for opioid use disorder, the isolating effects may be compounded. Electronic pillboxes provide an innovative strategy for improving medication adherence by reinforcing self-reliance through discrete, automatic, and customizable reminders. For our intervention, we selected an electronic pillbox that allowed for not only visual, auditory and electronic reminders but also enables patients to organize their medication by putting the blister packs into the pillbox. Since this data collection, we report no significant issues with the use of the pillbox, apart from power outages that affected patients' ability to recharge their device.

Information sharing: it matters who sends the reminders

Patients seem particular about who has what information, and overall, they seem to prefer that their medical information, especially HIV-related, stay within the confines of patient-provider relationships. Patients' desire for maintaining the existing relationship may be due to trust that has been built with their medical provider. To patients in this study, the source of healthcare feedback was important. Facilitators of implementation included patients' current mobile phone use for medication reminders and their trust in providers. Future interventions should involve two-way HIPAA-compliant texting with culturally-informed, empathetic content to facilitate secure communication with mutual consent.

Patients in this study were resistant to the inclusion of members of their personal network in their reminders. For this population of cocaine-using PWH, they seemed reluctant to burden family members with their healthcare or their recovery from addiction, especially since addiction is a chronically relapsing condition and their family members may already be fatigued with their situation. It is also possible that their personal social network could include individuals in their drug-using network, who may exacerbate their health and addiction conditions. Rather than further tax these tenuous relationships, participants seem to expand their networks by building trust with certain medical providers with whom they have built a rapport and who are already familiar with their HIV status and care. Providers and patients in the FGs designated case managers as the ideal people to communicate with patients. Among providers, case managers are assumed to have responsibilities of outreach to patients and the communication is also assumed to be bi-directional. Physicians seem to prefer more social distance from their patients out of a desire to protect themselves from miscommunication, missed contact, and potential liability.

New technologies mean new norms

The rise of mobile technology and related applications such as mHealth, means that new norms have to be established for its use. The responses from these FGs show that even for people who are unstably housed, there are opportunities for participating in mHealth interventions. Broad rules for effective patient-provider communication while maintaining patient autonomy, however, are still unclear. A comparison of provider and patient perspectives on mHealth for improving HIV adherence found that personalizing text messages, attention to timing, and confidentiality of messages were key factors for a successful text message reminder system (66). This study also uncovered structural reluctance to move American medical systems into more digital formats. Providers' workplaces seem to be barriers to digital communication with patients, although medicine in general seems to be earnestly moving in a direction to facilitate faster, more effective provider-patient interactions, through technology. These findings are consistent with White et al. (67) whose systematic review of health workers' utilization of mHealth in their workplaces found that infrastructure represents a barrier to mHealth uptake; our study, however, uncovers additional details relating to effective communication between patients and providers, specifically, that it matters which type of provider communicates with patients.

Limitations

Despite the many important findings gleaned from this study, these should be interpreted in light of some limitations. First, eight FGs is limiting, but the patient population has specific comorbidities that influenced the inclusion criteria. Also, combined drug use and HIV-related stigma complicated recruiting eligible participants. For the participants we did recruit, we did not collect demographic

information; our observation, however, was that participants were mostly aged 40–60. A different demographic, e.g., younger PLH might have yielded different results. The nature of FGs means patterns of reminder strategies among individual patients are vague, and so it is difficult to know if patients simultaneously used more than one strategy identified here. Also, we asked generic questions about the pillbox because we wanted responses about its potential capabilities to inform the version we ultimately chose for our intervention.

Conclusions

Key findings suggest that despite some notable restrictions on the content and who should be involved in mHealth communication, both patients and providers found potential merit in its application. Strategies that were identified as potentially burdensome (e.g., including families and peers) may still benefit from investigation because expressed preferences may not represent real-world experiences. Patient feedback about reminders was a main driver of our future directions. We incorporated findings into the design of a subsequent mHealth pilot randomized control trial in the following ways: (I) personalized feedback from a clinician along with automated reminders and feedback and (II) facilitated mobility and convenience by providing backpacks for all devices, considering HIV-infected participants' concerns about their transient and unstable living conditions.

This study addresses the urgency expressed by Volkow and Montaner (68) for individuals with substance use disorders and living with HIV to receive HIV testing, access to treatment, and support to remain in care. The World Health Organization (WHO) has identified five dimensions of nonadherence, including those related to social and economic structures, health system, medication types, medical condition, and patient population (69), which require innovative intervention tools like behavioral interventions (70). mHealth has the potential to address and improve health outcomes in each of these dimensions. More importantly, examining end-users' and stakeholders' perspectives is critical in developing effective mHealth strategies to help people manage their health behaviors.

Footnote

Conflicts of Interest: The authors have no conflicts of interest to declare.

Ethical Statement: The authors are accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved. This study was approved by the Institutional Review Board of Yale School of Medicine (IRB Protocol ID 1508016342). Informed consent was obtained from all participants before enrollment into the study.

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