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Authors

Nyamathi, Adeline
Smith, Donna McNeese
Shoptaw, Steven
[et al.](#)

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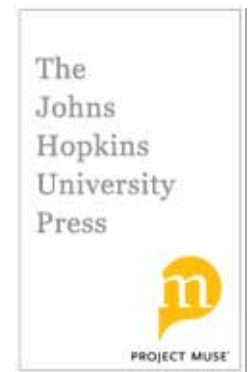
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Perceptions of Methadone Maintained Clients About Barriers and Facilitators to Help-Seeking Behavior

Adeline Nyamathi, ANP, PhD¹, Donna McNeese Smith, RN, EdD¹, Steven Shoptaw, PhD², Malaika Mutere, PhD¹, Allan Cohen, MA, MFT³, Israel Amrani, MFT³, Louis Morales, JD³, Viviane de Castro, PhD^{1,4}

(1) University of California, Los Angeles, School of Nursing; (2) University of California, Los Angeles, Family Medicine; (3) Bay Area Addiction, Research and Treatment, Inc.; (4) University of California, Los Angeles, Department of Psychiatry and Biobehavioral Science

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Abstract

Background: Among substance users, health seeking remains a major challenge for which few data are available.

Objectives: We sought to investigate the perceptions of methadone-maintained heroin users who are also problem or heavy drinkers, their barriers and facilitators to seeking help for substance and general and chronic care treatment.

Methods: A qualitative design using a semistructured focus group approach was conducted with a convenience sample of 41 adult clients of a methadone maintenance facility in Los Angeles.

Results: Findings revealed that discrimination was a major challenge experienced as a result of their methadone status.

Lack of primary care providers, limited access to health care facilities and access barriers were pervasive. Focus group participants expressed a desire for nonjudgemental and empathetic care that would foster respect and facilitate help-seeking behaviors through a comprehensive support system.

Conclusions: The need to design culturally relevant training programs was evident which included an integration of treatment, communication and societal issues.

Keywords

Methadone-maintained adults (MMAs), substance users, help-seeking behaviors, qualitative methods

Recent data reveals that 22.2 million Americans aged 12 or older were classified with substance dependence or abuse in the past year.¹ Of these, 3.3 million were classified with dependence on or abuse of both alcohol and illicit drugs. In addition, it is estimated that nearly 15 million Americans over the age of 12 have met criteria for alcohol dependence.¹ Despite the fact that fewer than 25% of users voluntarily enter drug or alcohol treatment,² there is a dearth of literature examining the barriers and facilitators experienced by these users. Common barriers experienced by injection drug users (IDUs) include lack of insurance, limited treatment access, aversion to treatment (particularly methadone maintenance), transportation, being homeless, and problems in dealing with childcare and child custody issues. Methadone-maintained heroin users are also more

likely than non methadone-maintained persons to voice complaints related to the attitudes of the treatment providers and lack of privacy in accessing methadone and needle exchange services as barriers to care.³ The individuals' belief in their ability to solve their problems by themselves is perceived as both a barrier and a facilitator in seeking successful treatment.⁴

Among drug and alcohol users, bad treatment experiences, stigmatization, disbelief in the effectiveness of substance treatment, and denial are the main barriers highlighted.^{5,6} When treatment-seeking behaviors of problem drinkers are considered, barriers include privacy concerns, the clients' belief that treatment is unnecessary, and practical and economic impediments. Facilitators include the negative consequences of alcohol on social functioning, social pressures to seek help,

the inability to solve ones' own problems, the need for a job, and religious and legal encouragement.⁷

Among a clinic sample of HIV-positive substance users, homelessness was found to be a particularly significant barrier to medical service utilization.⁸ However, personal and community resources were found to facilitate their use of health care services. Significant correlates to help seeking behavior among these IDUs included high-quality experiences of case management (an important source of assistance for navigating the health care system) and health insurance. Positive perceptions of the treatment providers' dedication and engagement have also been observed to enhance substance users' help seeking behavior.⁹

General health care-seeking behaviors still remain an unfortunate challenge for substance users and needs further investigation.¹⁰ Although substance users clearly utilize health service resources, most commonly the emergency room, for the myriad of physical problems they experience,¹¹ outpatient visits nevertheless remain suboptimal.¹² Additional perspectives provided by health care professionals on barriers for substance users in seeking treatment include the clients' lack of insurance; and agency bureaucracy. Treatment staff members have also cited lack of appropriate programs and the societal stigmatization of addicts as barriers to help seeking.¹³

The present study describes the first phase of a mixed-method (qualitative and quantitative) approach to understanding the barriers and facilitators of help seeking for substance and general health care treatment in a group of methadone-maintained clients, the majority of whom were also problem or heavy drinkers.

METHODS

Design

A convenience sample of 41 MMAs attending a methadone clinic in Los Angeles were recruited for focus group discussions about the barriers and facilitators they experienced in seeking general health care as well as substance treatment. The clinic population numbered over 400 and were balanced in terms of minority and white subgroups. This community-based, qualitative study engaged key leadership and staff of the clinic to assist in the study design, the refinement of the semistructured interview guide (SSIG) that guided the focus

groups, and analysis of the findings.

MMA participants were eligible if they were over the age of 18 and were enrolled in their methadone maintenance program for at least 3 months. A total of four focus groups were conducted in September, 2006. There were 8–11 participants per session, including 3 persons who chose to participate through individual one-on-one interviews as opposed to focus group sessions. This study was approved by the University of California, Los Angeles's Human Subject Protection Committee.

Procedure

Research staff visited the recruitment site and informed clients about the study by means of posted flyers. For those interested, after informed consent for the screening had been read and signed in a private room in the methadone maintenance clinic, the research staff administered a brief questionnaire to gather sociodemographic data and a screener for alcohol use and severity. Immediately after these documents were completed, a focus group was formed with discussions facilitated by very experienced qualitative researchers using a SSIG in private areas within the site. Each of the focus groups was audio-recorded on a cassette tape, with notes on nonverbal communication and other observations captured by a qualitative co-researcher. All respondents were paid \$10 at the completion of the 1-hour focus groups.

As appropriate to community-based participatory action research, community members were involved in the study design, assessment measures, study implementation, and interpretation of findings. The first author worked very closely with community co-author (AC) in all aspects of the study before grant submission and with ongoing study implementation after funding was obtained. This included forming the research questions, selecting the research site, and guiding the study implementation and analysis. This collaboration formed when the community partners invited the primary author to join them in designing the study. The concept of focusing on alcohol using methadone-maintained clients was the area of interest of the community partners. In addition, other community leadership, as reflected in co-authors, assisted throughout the study implementation and provided feedback and review of study findings and analysis. They also assisted in refining the SSIG in a culturally and linguistically

appropriate manner. This included rephrasing of sentences and adding or deleting questions that were originally drafted by the primary author and the primary community partner. Moreover, the entire community of counselors, nurses, and physicians at the site met with the research team frequently and provided feedback relative to the results and implications. Involvement of our community partners from the methadone maintenance site is a strength of the study and has led to

a greater understanding of the phenomena of help-seeking barriers and facilitators experienced by these clients. Table 1 displays the SSIG questions.

Data Analysis

Upon completion of the focus group sessions, the investigators oversaw transcription and content analysis of the taped recordings. The analysis was done directly from the

Table 1. Semistructured Interview Guide Questions

What You Know	
We want to know what kinds of health services do you seek or have used in the past few years. Let's go around the table.	
1.	<p>Please tell us what health services you have sought in the last few years. [Facilitator: use the following probes if participants do not mention these services or do not have anything to say]</p> <p><i>Probes</i></p> <p>Medical problems like a respiratory infection</p> <p>Birth control</p> <p>Vaccination</p>
Other health problems?	
2.	<p>Was there ever had a time when you had a health related problem but did not seek care for it, what was it that stopped you or got in the way?</p> <p><i>Probes</i></p> <p>Getting to the clinic; transportation problems?</p> <p>Embarrassed by your problem?</p> <p>Do not like the clinic staff?</p> <p>Hours of the clinic not flexible?</p> <p>Costs too much.</p> <p>Didn't have time.</p>
3.	<p>What, if anything has helped you seek and receive care when you have needed it?</p> <p><i>Probes</i></p> <p>Accessibility of the clinic staff?</p> <p>Knowing that the staff care about you?</p> <p>Worried about your health?</p> <p>Knowing it is important for keeping you healthy/safe?</p> <p>Knowing it is free</p>
Now, we would like to ask you a few questions about types of alcohol reduction services you or your friends have accessed.	
4a.	Where do you or your friends typically go to seek this care?
4b.	What kinds of alcohol reduction programs would you like to access or feel you need?
4c.	What are the barriers you experience when you request such care? What has helped you receive this care?
5.	What do you think might be reasons you or your friends might not get treatment for reducing alcohol use? What do you think has helped persons like yourself in accessing alcohol treatment or what do you think <i>would</i> help?
6.	How can the director and staff of your methadone maintenance clinic better enable you to access these services?
7.	How can methadone maintenance directors encourage their clients who abuse alcohol to seek such services within their methadone maintenance sites?

transcripts using the constant comparative method.¹⁴ This method involves a line-by-line analysis of the transcribed interviews by coding data into relevant sentences and phrases, which led to emerging patterns and themes. Concurrent coding and analysis continued until saturation was reached and unique categories were no longer identified. Trustworthiness of the data¹⁵ and control for naturalistic inquiry were ensured by validation of repeated themes from each focus group and feedback from community partners.

RESULTS

Sociodemographic Information

The participants ranged in age from 24 to 73 years (mean, 40.0). The majority of the MMAs were white ($n = 17$), followed by Hispanic-Americans ($n = 9$), and African-Americans ($n = 8$). Six were of mixed ethnicity and 1 was “other”; most were male ($n = 28$). A large percentage of participants consumed 12 or more drinks per day ($n = 12$; 29.3%), followed by 4 to 5 drinks per day ($n = 7$; 17.1%), 2 to 3 drinks per day ($n = 8$; 19.5%), or 1 drink per day ($n = 6$; 14.6%). Eight persons (19.5%) reported no alcohol use in the past 6 months.

Treatment Needs

For many methadone-maintained clients, services that were needed included drug and alcohol treatment as well as general health care, which ranged from the normal healthy occurrences, such as childbirth, to services for managing serious crisis experiences such as internal bleeding, severe victimization, and pancreatitis. The major barriers to seeking care cited by participants included financial, structural, and personal concerns. Some participants specifically detailed issues of stigmatization by health care providers, and perceptions of inappropriate aspects of current drug and alcohol treatment programs. Participants also offered advice on what would help to facilitate their seeking treatment and care, emphasized the significance of a nonjudgmental environment, and the importance of social support.

Barriers to Seeking Medical Treatment

Financial/Structural. Cost of care and lack of insurance were perceived as major barriers for many of the focus group participants who sought medical services. Without MediCal

or Medicare, participants felt that their choice of doctors was quite limited. Frustration was clearly expressed by one male client:

At times I've gone to different places, and if you don't have MediCal or Medicare which, if you're over a certain age, they won't give you MediCal or Medicare . . . you just have to go from avenue-to-avenue, door-to-door, and seek. And sometimes it's hard where you just say, “the hell with it!” (pardon the expression).

To make matters worse, the restrictions placed on the medical services allowed were quite complicated as one woman reported:

For one thing, it's a problem because of our MediCal cards. . . . They tell us that we need the red-and-blue card. And if you don't have the red-and-blue card, you only get a certain amount, or level of treatment and medication, you know . . . on the card.

Although lack of familiarity with available government programs created barriers for some, many clients also commented on the discouragingly long wait to see a physician for a medical problem. Some participants also advised that clients with chronic medical conditions such as diabetes and heart disease tended to ignore their health problems, simply because of the bother involved in seeking care.

Feelings of Stigmatization. The consensus of the groups was that methadone maintenance clients felt stigmatized and were “looked down upon” by medical clinicians. As a result, many clients chose not to tell health care providers they were on methadone maintenance. They also verbalized the sentiment that the doctors' personality and attitude has often been a barrier to their receiving care: “sometimes they're just not interested in what's wrong with you. They don't wanna hear what you have to say about what's wrong with you.” Others agreed that some doctors and nurses also looked down on them and do not want anything to do with drug-addicted patients, making them feel as if they are a “cockroach or something”; demonstrating “no warmth . . . no compassion.” This was particularly experienced by two women who reported excessive alcohol use:

like, they don't care about you. If you tell them you're an alcoholic, that makes you even less of a person. 'Cos, you know . . . “you're a drunk . . . you ain't nothin'.” They don't care nothin' about you!

Problem is, most doctors or nurses . . . When you go in for help, they . . . the expression on their face . . . their mannerisms . . . the way they treat you . . . makes you wanna leave. [agreement from group members]

A number of participants perceived that their health care providers do not understand addiction, and more important, do not understand the importance of methadone as a treatment medicine. These health care providers tended to blame the patient's opioid addiction as the source for every medical problem and would advise the clients to just stop and become drug free. Most focus group participants, however, argued that it is not that easy to stop their addiction, and that it can be even harder to taper successfully from methadone.

Another woman expressed the opinion that because she was on methadone and also drank alcohol, her health care providers did not want to give her help for the alcohol problem until she got off the methadone. A male participant echoed this concern based on his own, similar experience:

I went to the hospital because I thought I was having a heart attack one time. And they asked me what medications I was on . . . I said I was on methadone. They're like, "You need to get off drugs and then you'll stop having heart attacks."

Inappropriate Aspects of Current Drug and Alcohol Treatment Programs. The types of programs that exist for drug and alcohol treatment raised some other concerns for focus group participants. One man expressed the concern that "in-home"(residential) drug programs were a "rip off" because money is taken from homeless clients, and when the 6-month program was up, "they sent [the client] right back out there on the street with nothing." Another male was concerned that sober-living programs make it difficult to reenter if one were to "slip-up and have a drink." These programs require clients that have consumed alcohol to detox before being readmitted, which takes about 45 days. This was perceived as excessive.

Several males offered a number of observations from Narcotics Anonymous (NA) meetings relating to the staff running the meetings. The most serious concern was that people who were perceived as never being drug users were "*claiming* to be sober." However, according to one, "they are *hooked* on NA meetings, they are clique-ish and judgmental; and they push the message that you don't have any power on your own [in order] to reinforce dependency on their NA meetings."

Also, these participants noted these leaders would be continually smoking cigarettes and drinking coffee throughout the NA meetings which was viewed as hypocritical. "They just changed addictions!" As one woman explained:

That's why I don't like going to NA, because you've got these people who barely f***ing ever did anything! Don't know what it's like, except they snorted a little cocaine . . . And they're out there, self-righteous, spouting all the crap from the meetings.

Another female added: "Yeah! But they've never stuck a needle in their neck; they've never OD-ed; they never had to sell their a**; they've never had to commit a crime." One woman hated groups because she felt the clients were treated like children; being told what they had to do: "It wasn't even the group. It was us, as our . . . personalities as being addicts: *we* didn't like being told what to do, 'cos a lot of us have been told all our lives what to do." Her preference was for a gradual approach to group participation where it was a personal decision to be present.

Receiving Effective Treatment: What Works

Nonjudgmental Environment. Clients verbalized a great deal about what they wanted in a treatment program. It included a nonjudgmental environment in which everybody felt equal and enjoyed a sense of camaraderie. As one woman put it, "in a drug-addict's life, as in sober life, judgment is a big issue."

I think being able to relate to each other . . . you know . . . because you all have the same problem. . . . [A]nd you feel equal to everybody . . . that no one is superior, or better than you are, you know. I think that's what brings these groups together, and that's what makes them successful . . . is because everybody . . . you know, you walk in there, not feeling that anyone's going to judge you. . . . And you realize that you're not the only one going through everything you're going through. "Oh! That guy is/that woman is kinda like me . . . and she uses drugs." . . . I think heroin is—as opposed to other drugs—like it's kinda a loner drug. Like it scares people away a little bit.

A male participant expressed the idea that being an ex-addict was not a necessary prerequisite to becoming an effective counselor:

We have a saying, kinda like as substance abusers that, "How can you give me any kind of advice or not if you

haven't been an addict, or used?" . . . Now, that's B.S., you know . . . because . . . you really don't have to have that experience to be effective as a therapist and a counselor or what have you, because if you have that empathy . . . My first experience with treatment was with my drug-treatment program . . . and my counselor was just out of college . . . that was my first type of treatment.... She didn't have any experience but she had what they call empathy . . . you know what that is. . . . And she was very effective. Now, I know some counselors, they have all the experience in the world . . . they've been dope-fiends . . . but who are very *bad* therapists, you know . . . bad—you couldn't get anything from them. And what is important I think for individual therapists, or for therapists as a whole is that same thing we've talked about over and over again, is acceptance . . . empathy . . . er, you know, being able to listen . . . you know, don't have any preconceived, set ideas about your clientele or what have you. And, that's a start. . . . I'll put it like that. That's a start.

Thus, the participants focused more on the caring nature of the counselor, and on the counselor's ability to help addicts to see "the finer things in life . . . the things that they're really missin' out on." Keeping a record of where she came from was helpful advice one of the participants received from her sponsor:

You know . . . It's like sometimes people forget where they come from, you know. . . . The longer they're clean, they forgot . . . you know, how it was. You know, like my sponsor used to tell me, "Write down how bad it was . . . your last day out on the streets." And that helped me a lot . . . I used to look back and, "Oh, my god, I did this . . . I did this" and . . . you know, robberies. I did a lotta time.

For another addict, loving themselves was considered important, because when that stops, the drug abuse starts. "They abuse their body 'cos they don't care." Building self-esteem was considered important by many as well as trying to provide resources for housing, job skills, and so on. For others, it was financial aid, legal aid, and spiritual support. As one male described:

for those who have lost their jobs due to alcoholism, once they kick the habit an aid would be some kind of support or referral-system for jobs, activities, etc. to transition back into society . . . rather than going back to joblessness and potential homelessness, which would be a major setback.

Participants were quite interested in having an alcohol

treatment program offered in the midst of the methadone clinic. A small number of clients wished that they could also receive help from getting off methadone, for which one male conceded "This here's like a business. And their business is to keep us . . . drinking this stuff."

Use of Support Groups. A number of clients reiterated the need for support. They advised identifying the group of people who were serious about changing their lives, and having a support group with fun activities for them to engage in together. Two males agreed that "understanding" and "listening" would be important in the healing process as would having a therapist who demonstrates empathy, acceptance, and the ability to listen without prejudice. This was considered more important than a trained experienced counselor who creates barriers because they lack these key ingredients.⁴

Several of the women emphasized the need to have "somebody . . . that comes . . . to remind [them] . . . that they should be at this meeting on this day . . . or/and come and pick 'em up to see if they have a way there, to come to the meeting . . . because drinking . . . alcohol has a tendency to make you absentminded". Other suggestions included having a hotline that would direct them to an appropriate place to stay. As one male contended, "A person who is detoxing needs to be around other people who are reinforcing supportive messages, not isolated with their own problems and negative script." A related concern was raised on dwelling heavily on the "I am a drug addict" type of scenario, and missing the point that addiction is a symptom, not the problem itself. As this participant explained, the problem is people having "living problems . . . financial problems" and they turn to drugs and/or alcohol to cope.

DISCUSSION

Discrimination was clearly a major barrier experienced by focus group participants who recalled the disdain and callous treatment they experienced by medical professionals because they were methadone clients. The bond of trust that should have been their right to expect from health care providers, while struggling with their particular health issue at the time, became a negative encounter as a result of their methadone status. Anecdotal evidence of what the nurses and doctors did and said during these encounters has advanced knowledge in this area by revealing the pressing need for continuing

education programs for professional caregivers to sensitize them on the health care issues of this subgroup of clientele. As the Centers for Disease Control and Prevention report,¹⁶ “misunderstandings about the nature of drug addiction (not seeing it as a biomedical condition) are part of the reason why methadone maintenance treatment has sometimes been met with limited acceptance by communities, health care providers, and the public.” Educating nurses, physicians, and social service providers should include the costs to society for emergency department treatment and the costs of these clients returning to illegal drug use. This complex interplay of alcohol abuse and psychiatric problems should also be included in the education.

Another help-seeking avenue that was not perceived as particularly supportive of MMAs’ needs was in the context of traditional 12-step programs: Alcoholics Anonymous or NA group sessions. The NA program that some MMAs participated in the past had fallen apart because of issues of noncompliance with NA rules. There was consensus among focus group members on the desire for having a support group of their own, perhaps modeled after a 12-step program, wherein group support was felt and experienced, and empathy and forgiveness were foundational. There were also individuals who wanted to get off methadone and desired a support system for that. Thus, the need to expand the presence of social support has been clearly demonstrated.

What may be helpful in these instances is a discussion with a patient’s counselor to determine whether being drug free is a reasonable goal for the individual patient. Because these participants objected to being treated as children during help seeking, nondirectional therapies, such as Motivational Interviewing, may be of unique value.^{17,18} From this model, the therapist uses such skills as decisional balance to aid patients in arriving at complicated decisions about their health care and their livelihoods. Brief interventions, which are characterized by their short duration and low intensity, have demonstrated efficacy around the world in reducing risky alcohol drinking.¹⁹ Further, screening accompanied by brief intervention ranks as one of the seven most cost-beneficial prevention services.²⁰ For example, Motivational Interviewing incorporates reflective listening, eliciting motivational statements from clients, examining the positive and negative sides of the client’s ambivalent statements, and reducing resistance

by monitoring clients’ readiness and not pushing change prematurely.²¹ Findings from more than 30 clinical trials have reported brief Motivational Interviewing sessions to have benefit for alcohol and drug addiction, with an effect greater among heavier users of alcohol and drugs than among cigarette smokers.^{21,22} In addition, Motivational Interviewing was found to be effective with both substance-dependent as well as substance-abusing people.²¹ This is particularly promising; participants considered scare tactics to be a barrier to seeking health care rather than a facilitator. Findings of this study extend the potential adaptability of Motivational Interviewing as a useful strategy for use with methadone maintained clients who are abusing alcohol.

Methadone maintenance programs have come under increasingly heavy regulation and control within the United States for various reasons, thus limiting their flexibility and ability to respond to the needs of patients.¹⁶ This has created certain structural barriers for MMAs, which were generally acknowledged in discussions (lack of primary care providers, health care facilities, transportation issues, etc.), as were financial barriers (health care costs and lack of health insurance). However, much of the consensus appeared to respond to barriers that were on a more personal level at general health care facilities to counter the experience of discrimination by health care professionals who were often culturally alienated, inauthentic, judgmental, or hypocritical in their dealings with MMAs. Findings from this study should assist in designing training programs for medical nursing and allied health professionals so that care delivery be provided in a culturally appropriate and group-sensitive manner. The strongly articulated desire was for a nonjudgmental and empathetic environment that would foster respect and facilitate help-seeking behaviors through a collective and comprehensive support system, including referral, placement, and other social services.

It is important to realize that the public should have a major commitment to these MMAs, because they have chosen to leave opiates and seek sobriety. Loss of abstinence is a major threat to society. Most of these clients are infected with the hepatitis C virus or are at risk for infection and thus can spread this disease if they return to use of needles; others are also HIV positive. The costs for their medical care in the emergency department are many times higher than care provided by a

primary care provider. Last, but not least, if they return to crime to support an opiate addiction, the costs multiply by thousands.

If private physicians and nurse practitioners were able to dispense methadone, under the same controlled standards used for buprenorphine, and could also then provide the medical care, this might provide a more equitable situation. Relationships with an alcohol abuse treatment center would also be essential, as well as availability of psychiatric assessment and counseling. This policy change could go a long way toward creating equity in our system of treatment for former opiate addicts.

Much of the consensus of participants was that barriers were on a more personal level at general health care facilities, and there is a great need to counter the experience of discrimination by health care professionals who were often culturally alienated, inauthentic, judgmental, or hypocritical in their dealings with MMAs. Moreover, because mental health problems and substance use often share a close association, the need to consider this relationship as it relates to future directions for education and research is critical.

Findings from this study should assist in designing training programs for nursing, medical, and allied health professionals so that care delivery can be provided in a culturally appropriate and group-sensitive manner. Such programs should include the interplay of methadone treatment, the costs and risks to society if clientele return to opiate use, and methods of communication, treatment, and referral.

Limitations include a subset of methadone-maintained clients who may not be generalizable to the population of methadone-maintained clients who may have differed in terms of drug or alcohol use in different states or countries worldwide. Use of a small incentive may also have influenced their motivation to participate.

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