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Beliefs About Methadone in an Inner-City Methadone Clinic

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ABSTRACT *Despite being considered both the most effective treatment for heroin addiction and an essential tool in the prevention of human immunodeficiency virus (HIV), methadone maintenance (MM) is often held in low esteem by heroin addicts—even those in MM treatment. This survey examined current beliefs and attitudes about MM of patients at an inner-city clinic, and the personal experience and attitudes of these patients with this treatment. Consenting patients in a methadone clinic serving a poor population with high rates of human immunodeficiency virus infection were queried about their attitudes toward and beliefs about methadone using a 16-item questionnaire. Over 2 days, 315 questionnaires were completed (acceptance rate 40%), totaling 32% of the 1000 clinic patients. Nearly 80% believed that methadone had a positive effect on his or her life, but 80% were certain or unsure as to whether methadone is bad for one's health, and a similar percentage (80%) believed that discontinuing methadone was an important goal. Patients continue to have strongly negative attitudes toward and beliefs about methadone despite their acknowledgement that methadone has been very positive for them as individuals. As a result, many patients leave MM treatment prematurely, and there are usually unfilled slots in MM programs in New York City, even while continued need exists (e.g., less than 25% of the heroin addicts in the city are in treatment). The restrictive nature of many MM programs may account for these attitudes and beliefs.*

KEYWORDS *Addiction, Drug treatment, Heroin, HIV, Injection drug use, Methadone, New York City.*

INTRODUCTION

Methadone maintenance (MM) is the most effective treatment for heroin addiction.[1] In addition to sharply reducing or eliminating illicit opioid use, it also significantly reduces the risks of HIV seroconversion,[2,3] overdose, and suicide[4] among drug users. Furthermore, MM patients with human immunodeficiency virus (HIV) may remain healthy longer than do HIV-positive drug users not in MM.[5,6] The role of MM in HIV prevention is particularly important as injection drug use was directly or indirectly responsible[7] for a third of acquired immunodeficiency syndrome (AIDS) cases reported by June 2000 and directly responsible for over 45% of AIDS cases in New York State.[8] It is estimated that there are at least 600,000 opioid addicts in the United States[1]; however, there are only 115,000 methadone mainte-

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nance slots, allowing less than 20% of heroin addicts access to the best treatment. This deficit in treatment availability has been noted by the federal government and has led to a transition in program oversight in an effort to ease access to treatment.[9]

Despite these well-recognized benefits of MM, misinformation about methadone maintenance is common among methadone patients and their families, heroin users, and medical providers. These concerns have been documented in the literature for many years.[10–14] Patients believe that methadone is more damaging to health than heroin; specifically, the popular understanding is that it damages bones and teeth, and that achieving withdrawal from it is almost impossible. Even methadone providers misunderstand the roles of adequate dosing and long-term maintenance. In fact, these providers have been documented to offer insufficient doses and to encourage tapering to abstinence.[15]

In addition to misunderstandings about methadone, it is also apparent to patients that treatment entails still a higher degree of monitoring than do parole and probation, perhaps accounting for the term *liquid handcuffs*. While problematic patients may be evident outside many clinics, the more successful patients are invisible, often concealing their treatment from friends, employers, and even physicians.[12,14]

Thus, misunderstandings among patients, the misuse of methadone by providers, the burdensome regulation of treatment, and the stigma that serves to hide the successes of MM all combine to impede the goal of expanding methadone maintenance treatment to prevent HIV and decrease the harms of substance abuse. The NIH Consensus Development Conference found that the median mortality of methadone-maintained patients was 30% that of untreated patients, and that the financial burden of untreated heroin addiction is as great as $20 billion per year.[1]

However, little is known about patient beliefs about methadone; the few existing studies[11–14] were derived from qualitative interviews performed in the 1980s and early 1990s. Therefore, staff at the study site became interested in learning what beliefs and attitudes are common among the present patient population. This survey was designed to explore these issues both to better educate the current patients and perhaps to learn why many heroin addicts are out of treatment.

METHODS

A methadone clinic in New York City serving a poor, inner-city population was the site of this study. About 35% of the patients report AIDS treatment, and 15% are homeless or in shelters. Over 95% have their methadone treatment paid for by public assistance. The neighborhood (by ZIP code) is rated as a high-priority target for AIDS prevention because of high rates of opioid and cocaine use, high rates of sexually transmitted diseases, and numerous teen pregnancies, as well as high rates of HIV-related hospital discharges.[16]

Sample

A convenience sample consisted of all willing patients waiting in line at each nursing station for their methadone doses. They were offered a two-page questionnaire to be completed while waiting for medication. Patients were encouraged to add comments if they wished. Finished questionnaires, lacking identifying information to ensure anonymity, were placed in a box by patients. Assistance was offered if language, literacy, or eyesight presented problems.

Instrument

A new questionnaire was designed based on the literature,[10–14] on informal discussions with current drug injectors, and on the critical review of the drafted questionnaire by a focus group of patients attending the clinic. The questionnaire also solicited self-reported demographic information. It was distributed in February 1998 at two methadone maintenance units; 1 day was spent at each site. The questions are found in Table 1.

Patients were informed that they would receive the results of the survey. Several weeks afterward, the results were made available to the clinic patients in the form of a handout that included correct medical information about the issues.

Data were analyzed using the Centers for Disease Control and Prevention Epi Info 6 program.

RESULTS

Questionnaires were completed by 315 patients, representing about 40% of the approximately 800 patients asked, or 32% of the entire clinic population. Over 95% of patients who began the questionnaire completed all of the questions. The self-reported demographics and dose levels (Table 2) differed from the official demographics of the clinic population in several respects. HIV seropositivity appeared to be under-reported among study patients. Latinos were under-represented, non-Latino white patients were over-represented, and a portion of study participants did not report on race/ethnicity. Subjects were asked to report how long they had

TABLE 1. Questionnaire results

Statement	Agree, %	Not sure, %	Disagree, %
Methadone is bad for your health.	47	32	21
Higher doses of methadone are less healthy than lower doses.	39	30	31
Methadone gets into your bones.	71	19	10
Methadone damages the immune system (the ability to fight disease).	21	39	40
People should try to get off methadone.	80	11	9
I am afraid to tell doctors I am on methadone.	36	6	58
Heroin users who are not on methadone programs look down on those who are on methadone programs.	35	19	46
I am afraid to tell friends and family that I am on methadone.	53	5	41
Methadone encourages people to use cocaine.	25	14	62
Methadone is “liquid handcuffs”—coming to the clinic makes my life difficult.	55	14	31
Methadone has helped me change my life in a good way.	79	10	11
Counseling at the clinic has helped me.	68	11	21
Being on methadone helps people be more careful about using a clean syringe if they still shoot up.	41	16	43
Since I have been on methadone I am more careful about using condoms and choosing whom to have sex with.	60	9	29
Being on methadone helps drug users avoid getting HIV.	39	16	45
People would be helped if methadone were offered in regular doctors’ offices.	61	21	18

TABLE 2. Demographic characteristics

	Total clinic	Survey subjects
Gender*		
Male	60%	56%
Female	40%	41%
Age		
Mean	43 years	42 years
Range	24–77 years	27–72 years
HIV status		
Negative	44%	64%
Positive	36%	26%
Unknown	20%	10%
Race/ethnicity		
African American	40%	37%
White	11%	14%
Latino	49%	43%
Other/unknown	0.5%	6%
Length of time in methadone treatment		
Mean	Unknown	7 years
Range	Unknown	1 week–30 years
Current dose		
Mean	73 mg	69 mg
Range	5–120 mg	10–120 mg

*Gender not indicated by 3%.

been methadone patients; however, as many patients go from clinic to clinic, the facility has no way of knowing the average time on methadone among the population. The questions and the proportions of subjects answering "agree," "disagree," or "not sure" are shown in Table 1.

These patients appear to hold a set of beliefs about methadone maintenance treatment that both attribute highly negative qualities to it while acknowledging its helpfulness and value. Nearly 80% believe that methadone either is definitely bad or may be bad for their health, while an equal percentage believe that it has helped them change their lives for the better. The importance of stigma is also evident, with large numbers of patients expressing concern about discussing their treatment with friends and family (58%) or with physicians (42%). When this fear prevents disclosure to physicians, patients are in danger of untoward drug interactions.

Of the respondents, 80% believe that they should get off methadone, yet the average time on methadone was 7 years. While 39% believe that MM helps drug users avoid HIV, the majority were unaware of this benefit. Less than 20% do not find coming to the clinic to be difficult, and 60% believe that methadone could be offered in regular doctors' offices. Nearly 70% of the patients reported positive experiences with their counselors.

When patients were asked if their doses were appropriate, 72% believed the dose was just right, and 7% felt it was too low; however, 22% believed their doses were too high.

Correlations were sought between each question and reported dose range, time in methadone treatment, gender, and ethnicity. Women were significantly more

likely to disagree than to agree that "I am afraid to tell family and friends that I am on methadone" ($P < .01$). Women were also more likely to disagree that "being on methadone helps drug users avoid getting HIV" ($P < .01$). Otherwise, there was no relationship between these variables and knowledge or attitudes.

DISCUSSION

This study demonstrates that, among a group of inner-city MM patients, there are significant negative attitudes and beliefs about methadone and considerable pressure to leave treatment despite widespread agreement as to its personal benefit for them as individuals. Despite the clear evidence that almost 80% of this sample of patients believe that "methadone has helped me change my life in a good way," 78% of these same patients also believe (or suspect) that "methadone is bad for their health." Strikingly, this belief (that methadone is harmful) does not differ for those 20% of patients who believe that the treatment has not helped them (see Table 3).

This suggests the depth of the conflict (and pressure to leave successful treatment) that pervades many clinics due to the widespread negative views of methadone that we have documented.

It appears that patients are placed in a conflict between their successful medical care and their sense of self-respect and dignity. Rosenblum et al.[12] reported ambivalence among new and potential patients (with an average of 6 months of experience with methadone); the current study group had an average treatment duration of 7 years. Thus, despite these conflicting feelings and beliefs, they continue to take methadone for long periods of time. This dissonance is well summarized by a 34-year-old patient, who reported 6 years of methadone treatment uncertainty about its effects on his health: "It saved my life even though I find it to be liquid handcuffs." The difficulty of frequent visits to a methadone clinic expressed here has been noted in other research[17] and in government publications.[18] In addition, the concerns about the safety of methadone and the goal of getting off methadone are consistent with clinical observations. Specifically, many patients are reluctant to agree to a dose of methadone sufficiently high to extinguish heroin use and frequently request tapering despite having had numerous relapses to heroin use in the past.

Negative attitudes about methadone are commonly encountered in the addic-

TABLE 3. Beliefs among methadone maintenance patients

	Methadone has helped me change my life in a good way	
Methadone is bad for your health	Agree	Disagree and not sure
Agree or not sure	193	55
No data	3	0
Disagree	53	11

Chi square = 1.57; degrees of freedom = 2; $P = .457$.

tion treatment field and among peers. For example, methadone patients are not encouraged to speak in many 12-step settings,[19] they are excluded from many drug treatment settings, and they may even be denied life-saving procedures such as liver transplants.[20] Ideally, the clinic staff should assist the patient in separating the benefits of methadone maintenance from the unfortunate public perceptions through the provision of education and by generating confidence in treatment. While there are few studies on the attitudes and beliefs of clinic staff, several[15,21,22] have found that many staff also have a strong orientation toward abstinence and limiting the duration of methadone treatment. Ironically, the finding that the majority of the patients valued their experiences with counseling suggests that staff may bear some responsibility for common negative beliefs about methadone treatment, either because of their own biases or by neglecting to educate the patients.

The distribution of the results of the questionnaire with comments to the patients stimulated much discussion. Many stated that they were relieved to learn more about the safety of methadone. The dissemination of questionnaire information also generated questions and created a dialog among the counselors; it was later adopted by some as an informal educational tool, and it was the impetus for further training of staff.

There are a number of limitations in this study, particularly given its informal nature. The instrument was piloted in a small focus group, so there may have been areas of confusion. For example, the wording of a question on take-away privileges ("number of pickups each week") caused the data to be unusable. Thus, it was not possible to determine if the more stable patients differed in their beliefs. Offering the questionnaire to those in line to receive their dose provoked discussion of the questionnaire, methadone, and the clinic. While the investigators repeatedly emphasized the anonymity of the questionnaire, some participants may have felt some coercion to answer positively. General discussion may have influenced the questionnaire in a positive or a negative direction regarding methadone, particularly when patients with strong opinions spoke out. While the patients might have been less influenced if they had been invited to complete the questionnaire in a private, quiet setting after dosing, there would most likely have been a decreased percentage of client participation and greater selection bias. However, it should be stated that the investigators noted both methadone-positive and methadone-negative discussions and written comments reflected both sides.

CONCLUSIONS

This study suggests that methadone patients continue to be poorly educated about the safety and benefits of MM even after being in successful treatment for several years. The majority recognize some benefits of treatment, but misinformation and negative beliefs result in conflicts about their treatment. These beliefs may contribute to inappropriate discontinuation of treatment, which has been shown to lead to relapse in the majority of patients.[23] Further education is needed not only of the patients, but also perhaps of staff.

The findings of this study are consistent with earlier studies of methadone patients; however, there are still a few studies on the beliefs of out-of-treatment heroin users and none on the health care workers responsible for making referrals to MM. Thus, widespread misunderstandings about methadone and/or the restrictive requirements of clinics may play important roles in the decisions of most heroin addicts to avoid MM or to leave treatment.

In New York City, where about 60% of MM is publicly funded, there are an estimated 180,000 opiate addicts[24] and only 42,000 MM slots. While some New York City clinics have waiting lists, there is rarely, if ever, a day that there is not an empty slot somewhere in the city, suggesting that many users are simply not seeking treatment. Some of the concerns expressed by heroin users in this treatment setting may reflect the reason that many users avoid methadone maintenance. If the full benefit of methadone maintenance is to be realized, it is imperative that we have a better understanding of why patients are distrustful of and disaffected with treatment and act on that information to improve the use of this effective medication in treating opiate addiction.

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