

Methadone Advocacy:

The Voice of the Patient

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Abstract

This decade will see great strides in the acceptance of methadone treatment for heroin addiction, as a result of clear scientific and clinical evidence of its efficacy, and strong methadone advocacy. The new proposal for rule making (NPRM) will help the medical profession accept methadone treatment as beneficial for opiate addiction and realize that it should be more accessible to patients from trained physicians in the community. This will be the first step in reducing the stigma and prejudice that continue to hinder the availability of this lifesaving medication to all who need it.

Methadone advocacy has grown into a powerful network of groups working toward the same major goals. As the premier methadone advocacy organization and the voice for methadone patients, the National Alliance of Methadone Advocates (NAMA) will promote the view that methadone patients are to be judged by the contributions they make to their families and communities.

Key Words: Methadone advocacy, patient rights, stigma, staff and professional attitudes.

Introduction

STIGMA, PREJUDICE AND DISCRIMINATION have become the greatest barriers to recovery confronting methadone patients today (1–3). Securing employment and then maintaining a stable, responsible lifestyle is an important aspect of methadone treatment and recovery. But the employed methadone patients live with the constant fear that they will be discovered. Despite the fact that they are protected by the Americans with Disabilities Act (ADA), these patients risk losing their jobs merely for being enrolled in a methadone program (4). Many of these patients do not challenge their employers because they do not realize that it is against the law to be fired for this reason. Nor do they know how to proceed to challenge such a decision. Employment is not the only area in which methadone patients encounter

discrimination. They are also excluded from schools, training opportunities and service programs. Thus the road to recovery for methadone patients is difficult and filled with obstacles (5, 6). From the first day they enter treatment, methadone patients find opposition to their enrollment in the program.

Some of the greatest prejudice methadone patients experience comes from the methadone providers (7–9). Studies have found that approximately half of the programs administer subtherapeutic doses which encourage patients to withdraw prematurely (10–13). Other studies have found that professionals employed in methadone programs have a profound ambivalence regarding methadone treatment — which is not surprising considering the lack of training in medical and graduate schools (14–16). Patients become disillusioned about methadone treatment when they encounter condemnation and ambivalence from program staff.

The attitudes of a majority of methadone treatment patients are also influenced by the media, rather than by the results of scientific

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research (5, 17–19). This is not to imply that there are no good methadone programs. Yet all too often, patients find themselves fighting against a system that tolerates methadone maintenance treatment as a necessary evil. Until patients know what quality treatment is and believe that they are worthy of it, the situation will not change (20, 21). The formation of advocacy groups in which patients and enlightened professionals work together will lead to more methadone treatment programs that deliver quality treatment.

The National Alliance of Methadone Advocates

The National Alliance of Methadone Advocates (NAMA) was organized in 1988, when a group of methadone patients and professionals met to discuss the problems confronting patients and programs (22). Initially NAMA was envisioned as a small organization, the primary purpose of which was to change policy and educate the public and policy makers about the benefits of methadone treatment. However, as patients heard about NAMA they began to ask for help with problems that they encountered. Today, NAMA, with 48 affiliated groups in this country, serves as the premier methadone advocacy organization to represent the interests and concerns of patients.

Twelve foreign groups, themselves national organizations, together with those in this country, make up a worldwide network focused on the same basic goals (23). The Bruker Foreningen (Danish Drug Users Union) has established a community that welcomes active drug users and methadone patients in Denmark (J. Kjaer, personal communication). Their president, Joergen Kjaer, represents the interests of drug users on the National Drugs Advisory Board, which is a Danish policymaking council. The British Methadone Alliance (BMA) sponsored their first national methadone conference in April 2000. The BMA has also been outspoken this past year regarding the new proposed methadone licensing in Great Britain (24). Other affiliates include the Australian IV League, Gruppo SIMS (Italy), Bruker Foreningen i Tonsberg (Norway) and New Zealand Methadone Advocates. NAMA publications have been translated into Spanish, French, Danish and Italian. The total membership of NAMA, including the affiliates and chapters, is estimated to be about 15,000

individuals from fourteen countries (J. DePasquale, personal communication).

In the United States, those states with large patient populations have their own chapter of NAMA (25). Some of the NAMA chapters work within specific methadone programs, or at the local, state or regional level, to end the prejudice against methadone patients and protect their civil rights. These groups do not receive any funding and depend on the dedication of a few patients who have made a commitment to methadone advocacy.

A Change Is Due: New Rules and New Prospects

On July 22, 1999, the Center for Substance Abuse Treatment (CSAT) and the Substance Abuse and Mental Health Services Administration (SAMHSA) announced a new proposal for rule making (NPRM) in the Federal Register (26). Under this proposed new system, the federal regulations would be repealed and methadone treatment would no longer be regulated by the Food and Drug Administration. Oversight would be handed over to CSAT and methadone treatment, like all other areas of medicine, would be based on an accreditation system.

The intent of the NPRM is to transform methadone treatment, from a highly regulated procedure that physicians avoid, into a normal medical procedure. This will be the first important step toward incorporating methadone treatment into the practice of medicine (27).

The NPRM contains important changes for methadone patients. The accreditation system includes patient satisfaction surveys and encourages the participation of patients in clinic policy (26, 28). Perhaps the most attractive change for patients will include a more progressive take-home schedule. The NPRM uses guidelines that are similar to the current Federal Code to determine if a patient is sufficiently responsible to receive a prescription for take-home medication. These guidelines also liberalize the allowable amount of take-home medication. Under the current federal guidelines, a patient cannot receive more than a one-week supply of medication, with one dose to be administered at the clinic. The NPRM, however, extends take-home medication to thirty days, with one dose administered at the clinic. This is intended to facilitate a more tolerant system, which will allow a patient to undertake goals and projects

that were previously impossible, and, thereby, to promote self-esteem. A liberalized take-home policy will also have a major impact on physicians, who cannot now use their training or expertise to make judgments about which patients are responsible with their medication.

However, states and many local areas also regulate methadone treatment. Their rules are generally more rigid than the federal guidelines (28). At the present time, most of the states are reviewing their regulations. While some states may decide that they are responsible for regulation and become even more restrictive in regulating methadone, it appears that most are beginning to rethink their role. In order for methadone treatment to be accepted as a valid medical procedure, it is imperative that methadone treatment be prescribed by trained physicians in office-based practice (16, 27).

NAMA's Grievance Report Project

The announcement of the NPRM encouraged NAMA to develop a grievance-reporting system that would give patients the opportunity to register complaints against providers, state agencies, support services, criminal justice agencies, health-care providers, employers, vocational agencies, and others. These grievances would be investigated by methadone advocates rather than by agencies, which can be difficult to access. Most complainants need information and direction regarding their respective grievances. Under the direction of an NAMA advocate, complainants are informed about their rights and to whom they are to communicate if their rights have been violated (T. Scro, personal communication). At the end of the year, the grievances will be analyzed and reported to the respective agencies. The important aspect of this analysis is that trends will be examined, and first-hand knowledge will become available regarding practices in specific programs or states.

The primary complaint made to NAMA is that patients are not receiving an adequate methadone dose. Numerous studies have reported that the majority of programs do not prescribe an adequate dose (10–12, 29). A related complaint is that patients are not receiving adequate pain medication or, in some cases, any at all.

The second most common complaint concerns the administrative discharge policies of programs which arbitrarily discharge

patients without adhering to the recommended medically supervised procedures. Relapse into heroin use, criminal activity to obtain money to purchase heroin, or possible death by overdose are often the consequences.

Pain Medication and Methadone Patients

Methadone patients who need pain medication for medical reasons are at high risk for receiving inadequate relief of pain (30). There are a number of reasons for this. Many health professionals believe that methadone patients will obtain analgesia from the methadone, or they fail to realize the potential for tolerance in methadone-maintained patients. Also, the personal attitudes of the medical staff about illicit drug use may overwhelm the need to provide adequate pain relief. Patients' complaints are perceived as manipulations to receive opioids for other than pain relief. Some clinicians may believe that they are protecting the patient when they do not prescribe adequate pain medication. Unfortunately, the opposite is true, as inadequate pain medication, particularly in patients with a history of drug use, actually places many patients at risk of relapse should they attempt to find relief from pain through illicit means. The result is that many methadone patients who have needed medication for pain relief did not receive it.

With the high incidence of HIV infection and the increasing prevalence of hepatitis C virus among methadone patients, it is imperative that the medical profession recognize the need for adequate training regarding addiction. When treated humanely and with compassion, opiate-dependent patients should be no more difficult to treat than nondependent patients. The opiate-dependent patient deserves the same quality of care as any other patient.

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