Involuntary discharge from medication-assisted treatment for people with heroin addiction – patients’ experiences and interpretations

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ABSTRACT
AIMS – To examine what happens to patients who have been involuntarily discharged from medication-assisted treatment (MAT) with methadone or buprenorphine in Malmö, Sweden. MATERIAL AND METHOD – A total of 35 people, with a long history of heroin addiction, were interviewed, including ten women. Most interviewees were recruited among visitors with discharge experiences at the local needle exchange programme. The article focuses on these informants’ experiences and interpretations of being discharged. RESULTS – Discharge had little legitimacy and was perceived as unfair. Several of the interviewees went back to heroin abuse while others tried to create their own maintenance programmes by buying methadone or buprenorphine on the black market. Many resorted to crime or prostitution to make ends meet. CONCLUSIONS – According to National Board of Health and Welfare regulations, discharge and a three-month exclusion from all MAT is an appropriate response to violation of rules. Exclusion nevertheless led to harsh consequences. The interviewees’ living conditions were consistently impaired, as were their physical and mental health and contacts with family members, since they soon returned to a lifestyle and drug abuse similar to that before treatment.
KEY WORDS – heroin addiction, methadone treatment, buprenorphine treatment, involuntary discharge, disciplining.

Submitted 03.05.2011 Final version accepted 25.09.2011

Introduction
This article discusses the experiences of 35 patients in Malmö who shared a long history of heroin addiction and who were completely cut off from medication-assisted treatment (MAT) against their will and for a long time. It describes the changes in their lives after exclusion and considers different aspects of their current abusive situation. The study, based on interviews with patients, highlights their views on addiction and treatment.

Heroin is a powerful, illegal substance with a repressive effect on the central nervous system. Used regularly, it leads to a gradual increase in tolerance and to a psychological as well as a physical dependence. Heroin addiction entails an increased risk of premature death due to overdoses, violence, accidents, suicides or infectious diseases (Hser et al. 1993; Hall et al. 1999). The substance is expensive, and it is difficult to feed an addiction through regular earnings. Instead, as their tolerance increases, most heroin addicts are forced to resort to crime – such as theft and burglary and/or drug sales or prostitution (mainly
women) – in order to support their drug abuse (Bretteville-Jensen 2002; Debeck et al. 2007). A large proportion of Swedish heroin addicts are unemployed, plenty are homeless and many have a conflict-ridden relationship to their family (Socialstyrelsen 1997; Eriksson et al. 2003; Lalander 2003; Svensson 2005). The crimes following in the footsteps of addiction lead to large social costs for the police, customs and correctional treatment facilities (Amato et al. 2005; EMCDDA 2008). To combat drug abuse, the world’s nations, in co-operation with international organisations such as the United Nations and the European Union, carry out various actions to reduce the availability of drugs and to limit demand. One of the interventions on the demand side is treatment. For instance, the EU Drugs Strategy 2005–2012 and the Swedish ”National Plan against Drugs” emphasise the importance of providing treatment to reduce drug-related damages to both individuals and society (EU 2005; Regeringen 2010).

Maintenance treatment with methadone or buprenorphine is now the recommended treatment for heroin addicts (NIH 1997; Joseph et al. 2000; SBU 2001). The goal within the EU is to get as many heroin addicts as possible in maintenance treatment (EMCDDA 2011).

Sweden was the first country in Europe to establish maintenance treatment with methadone in accordance with the Dole/Nyswander model. This took place at Ulleåker Hospital in Uppsala in 1966. However, from the very beginning there was a strong opposition against this treatment, above all from people who preferred non-medication care and from those who felt that the model was contradictory to the restrictive Swedish drug policy (Heilig 2003; Johnson 2005). This ambiguity – manifested in the fact that maintenance treatment is evidently successful, yet controversial since the maintenance substance is classified as a drug – has affected both the extent and the design of treatment.

One of the manifestations of this ambiguity was seen when the National Board of Health and Welfare (NBHW, in Swedish ”Socialstyrelsen”) set an early limit to how many patients would benefit from treatment. In 1979, the limit was set to 100 treatment places (that year the number of opiate users was estimated to just over 2,000). In Sweden, the concern about HIV did not speed up expansion significantly. In 1992, the limit was defined as 450 places (of 5,000 opiate addicts); in 1998 it had reached 800 (with approximately 7,300 addicts); and in 2004, there were 1,200 treatment places (no estimate available for opiate addicts this year). The limit was not abandoned until 2005 (Johnson 2005). The model with a governmentally set restriction on the number of available treatment places has meant that there have constantly been long waiting lists for maintenance treatment. If someone has been forced to leave the programme, there have been many others waiting to fill the vacancy.

When buprenorphine, supplied as Subutex, became approved as medication in 1999 and could be prescribed by any licensed physician, there was a temporary opening in the strict regulation of maintenance treatment until 2005. As of 2005, the same rules have applied to both buprenorphine and methadone.

Furthermore, Sweden also emphasises the importance of patients not taking other narcotic drugs on the side (“side abuse”)
and not selling (or “leaking”) the maintenance substance. Side abuse increases the risk of fatal overdose (Fugelstad 2010), and leakage can lead to an increase of opiate abuse in the community. Different sets of rules are drawn up in treatment programmes to create a balance between the retention goal and the demand for control to mitigate the risks of side abuse and leakage (Johnson 2005; Davstad 2010). The rules are based on the NBHW’s “Regulations and guidelines for medication-assisted maintenance treatment in opioid dependence” (latest version from 2009) and on the manual supplied by the NBHW in 2004 (Socialstyrelsen 2009; 2004).

The importance of retention, that is, patients remaining in treatment, is stressed throughout, and high retention is a common indicator of the success rate of a programme (Amato et al. 2005; Berglund & Johansson 2003). Factors associated with high retention in methadone treatment are female sex, older age, lesser usage of cocaine and alcohol, high motivation, high methadone dose, better contact with the counsellor and higher levels of satisfaction with the programme (Kelly et al. 2011). Despite general agreement on the MAT’s significance, patients are still being cut off from therapy for disciplinary reasons, but usually they will have the opportunity to go to another programme (Reisinger et al. 2009).

There are an estimated 10,000 heroin addicts in Sweden (Sand & Romelsjö 2005). According to the NBHW, 32% of those with an opiate diagnosis received maintenance therapy in 2010 (Socialstyrelsen 2011, 2). On average, half of heroin users across the EU receive maintenance treatment, but the proportions vary in the EU countries between 0% and 60% (ECNN 2010). Sweden, then, is one of the EU countries which have a relatively small proportion of heroin users in treatment. One explanation is that the expansion of MAT has been relatively slow (Sjölander & Johnson 2009).

Patients who begin MAT often come from harsh backgrounds, with a history of mental problems, suicide attempts, poor physical health, crashed personal relations and experiences of incarceration (Socialstyrelsen 1997). They are to a higher degree unemployed, have lower levels of education and higher levels of mental disorders than clients with other primary drug addictions (EMCDDA 2010).

Given the patients’ problematic life situation, it is not surprising that many patients end MAT early (Vigilant 2008). Internationally, it is estimated that nearly 50% of those who enter methadone treatment are no longer in treatment after one year (Kelly et al. 2011). This is a problem, since according to a Canadian study, retention in treatment leads to less heroin use and reduced crime rates (Strike et al. 2008). One reason for the dropout is that the patient is dissatisfied with the treatment. By referring patients to other facilities, dropout can be avoided (ibid.).

The so-called treatment regime, or the approach to patients, varies in different maintenance programmes. The Australian researchers Fraser and Valentine (2008) note that although the rules on maintenance therapy differ between different countries, research on client experiences and views of treatment show many basic similarities.

In all jurisdictions the operational cultures of clinics and pharmacies vary, as
do the philosophies of individual workers, and both have an enormous impact on clients’ experiences. Treatment often involves daily pick up and can entail conflict, humiliation, long periods of waiting and regular intrusions on privacy. Equally, when respect and care are present and providers are adequately resourced, treatment is often valued by clients. (Fraser & Valentine 2008, 7)

Factors related to the methadone programmes may be more influential than patient factors for retention (Caplehorn et al. 1998; Reisinger et al. 2009). In the programmes which offered more contact with a counsellor and which had more experienced and committed managers, patients had less side abuse of illegal drugs (Magura et al. 1999). Further, programmes where staff can see the treatment as long-term or “indefinite” have higher retention rates than programmes where the staff’s goals are “abstinence-oriented”, aiming at patients’ leaving the maintenance treatment over time and becoming completely medication-free (Caplehorn et al. 1993; 1998; Gjersing et al. 2010).

**Study background**

Traditionally, Swedish maintenance programmes have stressed the need to exclude patients who do not follow the rules. During the period 1992–2004, 222 methadone treatments were started in Malmö. At the same time, 148 were ended. Some patients have been in and out more than once, and at the end of 2004, a total of 101 persons were enrolled (Socialstyrelsen 2006). Overall statistics for the Malmö programme after this year are not available because the NBHW’s “methadone register” was abolished in 2004, and the programme does not have published statistics of its own.

Earlier research shows that patients with opiate addiction who were involuntarily discharged from maintenance therapy face a significantly impaired life situation (Knight 1996) and significantly increased mortality (Grönbladh et al. 1990; Caplehorn et al. 1994; Zanis & Woody 1998; Fugelstad et al. 2007; Clausen et al. 2008). In Fugelstad’s 2007 study from Stockholm, the mortality rate was 20 times higher compared to those who remained in the programme.

Internationally, there is a widespread quest to make the drop-out patients return to maintenance treatment (Booth et al. 1998; Coviello et al. 2006; Goldstein et al. 2002; Hser et al. 1998). Such ambitions are not specified in the Swedish regulations or in the manual on maintenance treatment released by the NBHW. However, the need to “address the major risks that uncontrolled methadone programmes may bring about” is accentuated (Socialstyrelsen 2004). The rules specify the criteria that must be met for treatment to be initiated. For example, treatment may not be provided if the patient “is addicted to alcohol or drugs other than opiates in ways that may cause a significant medical risk.”

In addition, there is a clear regulation of the situations in which treatment must be stopped and when patients are discharged against their will. In accordance with the NBHW rules, the responsible physician must decide whether the conditions for exclusion are met or not. Chapter 4 of the "Regulations and general guidelines for medication-assisted maintenance treatment of opiate dependence" gives five reasons for discharge:
11 § A medication-assisted treatment for opiate dependence should be discontinued if a patient in spite of specific support and treatment efforts cannot be prompted to contribute to the achievement of treatment purposes, and the patient

1. has not participated in such treatment for longer than a week,
2. has repeated relapses into drug abuse,
3. abuses alcohol to the extent that it represents a significant medical risk,
4. repeatedly manipulates urine samples, or
5. according to a court ruling has been convicted of drug offenses or serious drug offenses, or has repeatedly been convicted of drug offenses of a minor nature where the offense was committed while in treatment (Socialstyrelsen 2009).

A person being discharged will not be allowed to turn to another treatment programme.

Medication-assisted therapy may not be given if a patient has been excluded from such treatment during the last three months. A situation such as this, where the highest responsible medical authority regulates the exclusion from treatment has no counterpart in other types of medical care in Sweden.

The regulations make an allowance for caregivers. They can ignore the three-month rule “if there are specific medical reasons for resumption” (ibid.). This exception has rarely been used in Malmö. In practice, the exclusion in Malmö is always longer than three months because of the long treatment queues.

Upon discharge, an individual assessment of the patient’s whole situation should be made, and a new care plan established, according to the NBHW handbook (Socialstyrelsen 2004). Patients should not be dismissed, but should be “offered a contact that enables an educational process aimed at making the patient better prepared to follow treatment at a subsequent treatment effort” (ibid.). The handbook does not discuss how the patient should be motivated to stay in touch with the programme during the time he/she is excluded from treatment, when appropriate medication cannot be prescribed, and the so-called banning period is not shortened no matter how anxiously the patient wants to return to the programme.

For this study, we have examined what happens to patients discharged from MAT with methadone or buprenorphine in Malmö. The study had a qualitative approach with an emphasis on analysing how patients felt about being discharged and about the changes it made to their lives. We also investigated patients’ earlier drug abuse and experience of previous treatment to get an idea of the severity of their past problems. The starting point for the project has been to approach the topics through the patients’ descriptions and perspectives.

Research questions
How do the patients describe their past heroin history?
What are their experiences of drug-free treatment and MAT?
How do patients describe the reasons for their discharge?
What legitimacy did the discharge have among patients?
What were the immediate consequences of the discharge?
How do the patients describe their current situation?
What differences are experienced compared to the time spent in MAT?
**Target group**
The study included patients who were involuntarily discharged in Malmö between 1 January 2000 and 1 July 2010. A total of 35 people were interviewed, including ten women. There are no data on the total number of discharged patients during this period, as this information does not exist. Some patients have been readmitted, some more than once. Some of them are included in the study. In these cases, the respondents were asked to describe, retrospectively, the situation during the discharge period. With respondents who had experienced multiple discharges, the interview focused on the latest discharge.

The respondents have either been patients at the Addiction Clinic in Malmö (16 people) or at Process (9 persons), a privately owned outpatient clinic that started in Malmö in October 2003. Ten people have experience from both units. At the time of the study, male interviewees were on average 43.2 years old, while the average age for women was 46.0.

**Study design**
The interviews were conducted by social worker Magnus Andersson at the Infection Clinic’s needle exchange programme (NEP), with the exception of one interview carried out by researcher Bengt Svensson. None of the two authors has any connection to the MAT programme. Most interviewees were recruited among visitors at the NEP, but a few have visited the clinic to see a doctor for treatment on infections or have personally contacted Andersson, because they were interested in being interviewed. In a few cases, Andersson met with former patients in public places in Malmö and asked them to participate. Patients received 150 SEK of financial compensation in the form of a prepaid mobile phone card. Andersson has been a counsellor at the NEP for more than 20 years and has an extensive network of contacts among people who inject drugs.

The interviews were conducted between 2008 and 2010. Among the interviewees, the average time span since the last discharge was 30 months, with the most distant discharge having taken place ten years ago. It is our impression that the interviewees have attempted to answer the questions as best they can, with the limitations that memory sets. Despite the time interval and the fact that several patients have been discharged on more than one occasion, the interviewees reported a clear and consistent picture of how they had experienced the last discharge and how it changed their lives. The discharge situation was an extraordinary event, and patients’ descriptions relate to various aspects that are essential to everyday living conditions (housing, health, drug use, etc.). This may explain why they have been able to provide detailed recollections. Similar descriptions and themes appeared in several interviews. There was consistency in the descriptions of the individual interviews when areas of questioning were closely related (see McIntosh & McKeganey 2002).

The interviews were structured around a questionnaire with open questions. They were recorded on MP3 players. In the meantime, the interviewer kept detailed notes in the interview guide to facilitate processing and as a precaution if the recording should fail. The interviews were then transcribed word for word. Further processing of the empirical material was
done by the researchers, first going through the written responses in the interview questionnaire to get a complete picture of the material. The interview responses were then categorised and sorted based on each question to provide a quantitative description. In the end, the transcribed interviews were subjected to a qualitative analysis of the interviewees’ descriptions of their experiences. In this analysis, the focus was on identifying key themes and individual markers in their stories (cf. Miles & Huberman 1994; Hedin & Månsson 1998; Kvale 1997). At this point, the interview statements used in this article were selected on the condition that they represent a typical or otherwise particularly enlightening interview response.

We asked all interviewees for permission to read their patient journal at the Addiction Clinic. All gave their permission, which suggests that the interviewees had significant confidence in the interviewer and in the project. (The follow-up of these journals is carried out in a separate study, where we focus on the interaction between patients and programmes). This article highlights the severity of the interviewees’ problems, in addition to their experiences of discharge and life circumstances after discharge.

Results
Abuse prior to maintenance treatment
The involuntarily discharged interviewees have a substantial and long-term heroin addiction behind them. Some were already present in the early 1970s when morphine base appeared in Malmö, and have since moved on to heroin, interrupted by periods in prison, in drug-free treatment and maintenance therapy. For others, the drug habit has developed in conjunction with the more recent heroin waves.

I started in 1983, when I was 22. Before, I had taken amphetamine for five years. The first month I smoked the heroin, then I started to inject. It took me two weeks to become addicted. Since then I have taken heroin. That will be 26 years. Man, 48.

I started with alcohol, butane gas and hash when I was 14–15. A few years later I took amphetamines. I started on heroin when I was 19–20 years. Was hooked almost immediately. Always liked downers. In addition to heroin, I’ve used pills and hash. Man, 24.

Of those interviewed, only five had begun in the 2000s. Considering that recruitment of new heroin users has continued in the 2000s, this number is somewhat surprising. One explanation may be that it takes a long time after heroin onset to seek maintenance treatment. Perhaps the programmes are less inclined to discharge young patients. A third possible reason is that the average age is high at the needle exchange programme, where the discharged interviewees were recruited. This may indicate that we have missed a few of the younger addicts.

<table>
<thead>
<tr>
<th>Years of heroin addiction</th>
<th>Men</th>
<th>Women</th>
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<tbody>
<tr>
<td>1–5</td>
<td>1</td>
<td>1</td>
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<td>6–10</td>
<td>4</td>
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<td>11–19</td>
<td>10</td>
<td>1</td>
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<td>20+</td>
<td>10</td>
<td>6</td>
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<tr>
<td>Total</td>
<td>25</td>
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Experiences of abstinence-oriented treatment
Ever since the start of the Ulleråker programme in 1966, the set of regulations has demanded that people entering maintenance treatment should have made serious attempts to try abstinence-oriented treatment first. The idea is that no one should be unnecessarily placed under maintenance treatment. From the start and during the following 23 years, there was a requirement upon entering that you should have made at least three documented attempts with drug-free treatment (Grönbladh 2004). In the NBHW’s guidelines from 2004 and 2009, this is no longer such a formal requirement. As it has become increasingly accepted in Sweden that maintenance treatment is an evidence-based method, the requirement to have tried other treatment has been abandoned. This does not alter the fact that all but four of the interviewees had tried abstinence-oriented treatment to a varying extent. In the group, the longest duration of such treatment was four years, but most people stated a total treatment period of six to twelve months.

The list of treatment options is extensive and includes both treatment homes/rehabilitation clinics with a psychodynamic and/or milieu therapy approach and those based on the Twelve Step programme. If you have been in treatment during the 2000s, it has most likely been a treatment based on different varieties of the Twelve Step programme. Of those interviewed, one person was waiting to go to voluntary abstinence-oriented treatment. Of the 35 respondents, 29 indicated that they did not perceive drug-free treatment as an option, but wanted maintenance treatment in the future.

Duration of maintenance treatment
The interviewees also have extensive experience of maintenance treatment, although the difference is substantial between them. One man had been enrolled in maintenance treatment for 17 years. He was discharged after having cheated with several urine samples.

Tabel 2. Time in maintenance treatment according to gender

<table>
<thead>
<tr>
<th>Time in maintenance treatment</th>
<th>Men</th>
<th>Women</th>
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<tr>
<td>&lt; 1 year</td>
<td>6</td>
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<tr>
<td>1–2</td>
<td>5</td>
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<td>3–6</td>
<td>8</td>
<td>5</td>
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<td>7–10</td>
<td>3</td>
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<td>10 +</td>
<td>3</td>
<td>–</td>
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<tr>
<td>Total</td>
<td>25</td>
<td>10</td>
</tr>
</tbody>
</table>

Most of the interviewees had experienced more than one treatment episode, partly because they had tried the privately run Process in addition to the public health care’s Addiction Clinic, partly because they had repeatedly been enrolled in the same programme. Without exception and according to their own admission, they had had to wait during exclusion periods before being given another chance. Nine people (four women) had participated in one single care episode. Fifteen (two women) had had two admissions, while eight (three women) had experienced three admissions. Two (including one woman) had been through four admissions, and one man had participated in maintenance treatment on five occasions.

Discharge circumstances
The interview responses regarding reasons for discharge reflect the interviewees’ recollections and experiences. They are
not descriptions of an objective reality, just as reading journals does not provide the reader with objective knowledge about reality. In a conflict, severe enough to cause such drastic consequences as a discharge from medical treatment, it is reasonable to assume that both sides convey an image that supports their own experience and their own definition of the conflict. Although a positive urine test is a seemingly unproblematic objective indicator of side abuse, there is a subjective element related to the extent to which positive urine tests are accepted before discharge occurs.

In Swedish maintenance programmes, it is not accepted that patients use illegal drugs or psychopharmacological drugs obtained outside the programme. In addition, excessive alcohol use can lead to discharge.

"I was discharged because I smoked hash. I’ve done it since I was 13, and it is something I miss terribly when I’m in maintenance treatment." Woman, 49.

"Their explanation was that I had been warned for side abusing benzodiazepines, so they told me to drop it. Finally, I ended up in detox, and was taken off benzo completely. And I was there for three weeks and started feeling better and better, and then they arrive from the methadone programme and just sign me out. I think they did wrong. They see that I really wanted, and I struggled to get out of this circle of pills, you know, get out of it... They don’t throw diabetics or heart patients out when they cheat with their medication and stuff ... It is a disease. They say it is and then they do this. They’ve seen that some of those thrown out have died, they haven’t learned from that, the fact that people die when they get discharged." Man, 41.

"I took amphetamines to have sex, and because I felt fat." Man, 38.

Notably, almost all the men bring up side abuse as a primary reason for discharge, but it only applies to three of the ten women. This may indicate that side abuse by women is tolerated to a greater extent. In several cases, there is a combination of causes, exemplified by the client experiencing that there has been a conflict between him/her and the programme and that a relapse has been used as an opportunity to implement a discharge.

"There were many who couldn’t speak up for themselves, so when I thought it was wrong I went in between. So they called..."
me in and said you shouldn’t get involved, because you do not know what’s behind. I was disturbing the peace. That’s why I was kicked out. For getting too involved, because I think there was too much injustice there. They said that I was not in time and that I could not handle that and then I was positive for benzo and, in connection with that, I was discharged. Man, 50.

Each discharge has formally been preceded by a decision made by the physician responsible. In reality, it seems that on several occasions it is the non-medical staff who wield decisive power. The decision has had the character of a collegial, collective agreement. The NBWH’s discharge guidelines have served as principal points of reference to the decision.

Many of the interviewees claim that the threat of being discharged means that they must try to avoid conflicts with staff and act as well-adjusted patients. The staff are seen as inspectors, not helpers that you can trust.

The staff feel like enemies really. If you don’t jump when they say "Jump!", then you know what happens. Then you can slip away. Really, those are the people one has to rely on! Woman, 44.

Upon discharge follows the banning period, which formally has lasted from six months to a year for the informants. However, in practice the term has been much longer since those who have been discharged are placed at the bottom of the waiting list. The ban means that the maintenance treatment programme is relieved of its responsibility for the client’s substance abuse problems. Care responsibilities are now transferred to social services, which according to the Social Services Act are ultimately responsible for the necessary assistance to the citizens. However, the social services’ opportunities to act are limited by the fact that they cannot provide the treatment option that is evidence-based and that the client previously selected – maintenance treatment.

In this situation, the remaining option for the social services is to try to convince the client to choose a treatment that he or she usually does not primarily want, such as the Twelve Step programme, or to settle for providing accommodation and subsistence. Powerlessness in the choice of treatment thus befalls both client and social services.

**The legitimacy of discharge**

Accepting something as legitimate is to perceive it as obligatory and morally justifiable (Engdahl & Larsson 2006). The interviewees were asked the question “How do you feel about your discharge?” They were consistently highly critical and thought the discharge was unjust. Dissatisfaction centred on the rules themselves and on the staff’s unfair assessments of critical events. In addition, the disproportionate consequences of discharge for the individuals were highlighted. Below are examples of the critique provided by the interviewees:

1) Their discharge was unjust when compared to rule violations by other patients in the programme which did not lead to discharge.
2) The programme staff took the opportunity to exploit a minor misstep, because
the patient was perceived as overly critical and outspoken.

3) The discharge was preceded by the patient having threatened staff, but too much was made of these threats, because inexperienced personnel interpreted outbursts of anger in an unprofessional manner.

4) The patients were discharged from a treatment that was perceived as medically necessary.

5) The discharge occurred at a time when the patients were particularly vulnerable and when they actually needed more support and help instead of suspension from treatment.

6) The patient did not receive a proper warning before discharge.

7) Discharge announcements were delivered by telephone.

In the interviews, patients referred to being discharged as "a mess", "a shock", "deeply unfair", "a death sentence", "like being placed in front of a firing squad", "inhumane", "insane", "totally insane" and "a disaster". A total of 31 of the 35 informants expressed dissatisfaction with the decision.

However, four people – all men between 35 and 50 years of age – accepted the decision. "It was OK. I had many positive urine tests." "It was warranted. I did not follow the rules." One of them had intended voluntarily to sign himself out since he did not want to stop smoking hash. After five consecutive urine samples that were positive for cannabis, he was discharged, which he accepted. He planned to continue maintenance treatment under his own management, using Danish methadone tablets. In other words, he preferred to obtain tablets illegally to be able to keep smoking hash.

Life conditions after discharge

Generally, discharge was followed by phasing out of the medicine offered by the programme. The understanding among interviewees has often been that the withdrawal period is too short, or that it is too much trouble to get lower and lower doses at a time when their situation is drastically deteriorating.

Then I should be phased out for three weeks but then, doing this bike ride back and forth every day and stuff. No, I couldn’t care less, so I stopped right away. Woman, 48.

After withdrawal or instead of withdrawal, the patients consistently started abusing drugs, usually heroin and illicit methadone or buprenorphine.

Yeah, at the beginning there were thoughts of suicide right away, wasn’t there, cause … At the same time as I was discharged from treatment I also lost my home and became homeless. I hung in there for three weeks. From the day I was discharged, I made it for three weeks, and only took illegal methadone, but then it went on to heroin. Man, 45.

Many had several years of illicit drug use behind them, with interruptions during prison terms, stays at treatment facilities or in maintenance treatment. When they were forced to discontinue treatment, they went back to using illegal narcotic drugs.
I was doing heroin from 1988 to 2000, except for a few periods when I was in residential rehabilitation. Then I got methadone, which I had for seven years. After discharge, I went over to amphetamines and I have continued with that. And I smoke hash every day. Heroin, I have probably just taken that three times since discharge, and I have not taken methadone or Subutex either. Woman, 44.

This woman was the only one not to return to opiates after discharge. Originally, she went into heroin addiction when she met a man who was an established heroin addict. When she was discharged from the programme, her relationship to this man had been over for some years. After discharge, she chose to begin with amphetamines and change her social network.

No one described having switched to a non-medication treatment after discharge. Many lost their homes and became homeless because their housing was linked to participation in the maintenance treatment.

At the same time as I was discharged from treatment, I was also discharged from my accommodation. Here, they put me on the street with my dog. Now I live a bit here and a bit there. The City Mission shelter. Otherwise, I can usually stay at a friend’s place and that, too. Man, 28.

Almost all interviewees described deteriorating relationships with their families. Likewise, almost all described a deteriorating physical and mental situation. A couple of them mentioned mixed feelings. There was both a sense of relief of no long-
er being stuck in a position of dependence in relation to the clinic – ”a heavy weight has come off my shoulders” – and concern about getting hold of heroin, methadone or Subutex on the illicit market.

The use of illicit methadone or buprenorphine
Leakage occurs from the Swedish programmes as well as the nearby Danish schemes. It stems from patients in the programme who have negotiated a higher dose than they need and then sell part of it. The money is used to pay for their livelihood or to supplement methadone with illicit drugs, medication or alcohol.

I have bought from other people (in the Swedish programmes), and sometimes I have gone to Copenhagen. But it’s expensive to go there, and it is expensive with methadone, and it’s not as easy to get hold of methadone and Subutex as it was before. But it’s cheaper than heroin in any case, and I’d rather prefer to take that, to buy that, rather than to throw away my money on heroin which is much more expensive and nowadays doesn’t even make me feel good. Man, 35.

For those discharged, leakage represents an essential survival factor. This becomes remarkably clear in the interviews in which a majority of the interviewees claim to periodically having used methadone/buprenorphine as an alternative to heroin. At the same time, leakage becomes a risk factor if maintenance drugs reach the “opioid-naive people”, those who have not developed a tolerance to opioids (Fugelstad et al. 2010).
Financial support
When the interviewees were forced to leave maintenance treatment, their finances deteriorated dramatically. Instead of getting medication that was free, they were forced to buy heroin or illegal methadone or Subutex. Of the 35 interviewees, 13 (including three women) got involved in crime. Four of the women returned to prostitution, which they had left behind while they were in maintenance treatment. This had been their main source of income before entering the programme.

I street-walk now. During treatment, I got by on my pension. Woman, 46.

The remainder of the patients try to survive on welfare payments or pension. Some sell the street newspaper Aluma. A woman who had been able to establish a social position during the treatment used her savings. Many interviewees describe a combination of different methods to raise money for illegal drugs.

I receive welfare payments and then I live a lot on, what the hell can I say, helping others. That people give me money and I’m running around fixing stuff, and I get for fixing stuff. This is above all what I do. For very short periods I, myself, have sold, but it’s not really something that I like. I’m not particularly prone to violence, and you really have to have some, yes, a little ... Yeah, cause I mean anyone can take out a knife and put it by my neck and say, ”give me the stuff, give me the money” and I don’t know if I dare to fight back in those situations. Man, 36.

Welfare payments constitute the foundation. Former patients may then resort to crime to handle their drug use when the money is gone. Many of the interviewees describe how they try to minimise criminal activity in order not to risk ending up in prison again. For women, prostitution is the expected way within the subculture to make money (Svensson 2005). It is still a stigmatised activity, however. A couple of the women stress that they have not turned to prostitution.

Current state of drug abuse
Keeping in mind that the interviewees were recruited at the Infection Clinic’s needle exchange programme or because they had an acute infection, it is not unexpected that almost all are still actively abusing, unless they have returned to maintenance treatment. Their life situation is the second worst. Those with the worst outcome are the ones who died after discharge.

Right now I’m on both heroin and amphetamines. And doses are getting higher, more and more, really, almost every day, but then I need the heroin to be able to ... It comes first hand, like. If I’m going to a meeting or something like that and I don’t have heroin, then I go and do everything beforehand, so I’m getting my dose before I go to the meeting. Just like it will have to wait, huh, it must come first hand. It controls me now, the drug, my schedule and everything. And I do not want it to be like that. I feel I am on the wrong path. I have lost my footing. Man, 37.

I was discharged 1,000 days ago, exactly. That is 1,000 days without meth-
adone. It’s heroin instead. During the time I have been out in the cold, it has been the same as before. So, yes, one and a half grams of heroin a day. Or as much as you can afford simply, what the wallet allows. It’s not certain that it’ll be that amount as it goes up and down, you know. Therefore, one can never say exactly. Man, 55.

Since their average age is slightly over 40, most of the interviewees have survived long-term addiction. Those most vulnerable in their generation of heroin users have already died. The interviewees therefore have a survival capacity to help them out when the notification of discharge arrives.

When I was discharged from methadone and so, yes, then I took about two grams of heroin a day cause I didn’t back down through withdrawal either, sort of, rather I started directly, sort of. Also, I take speed sometimes actually. That is unless I have something else. I must have something in my body. That, I must. Man, 52.

Really, I was so mad because I thought they should not be able to bring me down. So, somehow I became strong. I went back to addiction. I did that immediately. Was on it for two, three months. And then I was so pissed off with the whole situation so I switched off from all that shit and went overseas and was back to zero. Was away for a couple of months. Then I was cured for six, seven months. Then I couldn’t handle it anymore, and then I went back on heroin again. Woman, 53.

There are no figures from Malmö showing how many have been able to leave opioids totally after discharge, but judging by other studies it is likely that success stories are rare (Hser et al. 2001; Johnson 2005). Eight of the interviewees (including six women) have returned to MAT. A 40-year-old man is now free from both legal and illegal drugs and has a job to go to.

Discussion

The patients in this study describe a life filled with contrasts, beginning with a pre-maintenance treatment period of intense heroin use, progressing to a relatively harmonious period of treatment and ending in dramatically changed living conditions when forced to leave treatment. The outcome of their discharge is that they go back to the same destructive heroin addiction that they had been caught in before.

According to the interviewees, MAT meant improved mental and physical health, better finances and living conditions. The patients established better relationships with family members and reduced criminal activities. When they were locked out and returned to heroin use, it led to a great strain on their health and to a socially disadvantaged position. This often led to homelessness, considerable problems in family relationships and involvement in intense criminal activity to make money for buying heroin.

The discharge had little legitimacy among the interviewees and was perceived as unfair. In some cases, their arguments dealt with experiences of staff values during conflict situations related to discharge. Some questioned staff assessments, which they considered inaccurate and unfair. Others argued against the regulatory policy...
and felt that it should not be possible to discharge people from this type of medical care at all. A third line of argument focused on consequences of discharge. Given that discharge meant a relapse into heavy drug use, it should not have taken place.

In the first case, the interviewees felt that they had not done anything that should cause a discharge. In the second and third case, they admitted violations to rules but questioned the regulatory framework and/or referred to the inhumane consequences of discharge. By moving focus from their individual actions to the regulatory framework or discharge consequences, they were able to see themselves as more or less innocent victims even if rules had been violated. With a shift in perspectives discharge can always be regarded as illegitimate. Nevertheless, given their position of dependence in relation to the programmes, the interviewees’ experiences are essential to understanding the various perspectives related to the discharge practice.

Generally, the vast majority were satisfied to receive maintenance medication and were set on returning to treatment as early as possible. Many were critical of the maintenance programme’s regulatory framework and policy, but since they had no choice, they were keen to return to the same programme. Interest in drug-free treatment was low.

According to many of the interviewees, detoxification from methadone was painful, and the only possible solution to withdrawal symptoms was to return to heroin. Some had tried to establish their own maintenance programme by buying illegal methadone or buprenorphine from patients in Malmö or Denmark.

Notably, Swedish maintenance treatment places the patient in a particularly weak position compared to other drug treatment programmes. The American organisational researcher Albert O. Hirschman has introduced the concepts exit and voice as two strategies of resistance available to dissatisfied consumers and a third customised option that involves swallowing discontent and being loyal (Hirschman 1970). Choosing ‘exit’ is to leave and move to another organisation, while choosing ‘voice’ means raising your voice in protest. Both options are highly problematic for MAT patients. If they leave the organisation, they are forced to wait before they can access medication again. According to some of the Malmö patients, those that protest risk being excluded for rule violations, as they have made themselves inconvenient. They are therefore forced to remain loyal and adapt to the organisation.

The discharge and banning period rules of the NBHW become medically as well as ethically problematic, as patients have been placed on a highly addictive medication. They have a physiological attachment to the programme through the medication provided. The American social anthropologist Phillipe Bourgois is one of the critics of methadone programmes for that precise reason:

Researchers are so uncritically immersed in the disciplining parameters of their biomedical framework that they fail to recognize that it is the painfully physiologically addictive properties of methadone that reduce even the most oppositional outlaw street addicts (like Primo in East Harlem or more broken-down Harry in San Francisco) into stable patients once their bodies have built up a large enough
physical dependence on methadone to make it too physically painful for them to misbehave (Bourgois 2000, 183).\textsuperscript{13} Accordingly, disciplining takes place in the interaction between drug dependency and the staff’s instruments of power allowing them to turn off medication. The consequences of punishment can initially be seen in a prolonged withdrawal period, which is particularly pronounced in the case of methadone.\textsuperscript{14} Subsequently, the punishment is enhanced by the banning rule, stipulating a long time outside treatment.

**Conclusions**

In recent years, a tolerance for side abuse has increased in the Swedish programmes, but discharges are still carried out regularly, and the NBHW’s banning period regulations are still in force.\textsuperscript{15} In an evaluation of maintenance treatment in Jönköping, patients wondered why they could not take tranquillisers like any other people in the community (Johnson 2011). Methadone does not work against the high anxiety levels which many patient have. A social worker who works closely with MAT patients describes the dilemma (ibid.):

> These patients have not seen side abuse as something that must be adjusted. For them, the problem has been that they are not allowed to be side abusing, as this has filled an important function for them in various ways.

A detailed regulatory structure provided by the NBHW is probably helpful to staff working with maintenance therapy. The rules can support them in making decisions about enrolment and discharge. This implies that responsibility for a patient’s fate after discharge can be attributed to the regulatory system. “We must follow the Board’s rules”. If rules are missing, room for action in the individual programme (and for the responsible physician) increases, but so does the staff’s personal responsibility for decisions taken.

The NBHW allows Swedish maintenance programmes to discharge patients for violation of rules. Such a sanction, according to our interviews, creates an adherence to the programme among patients. In an international comparison, the frequency of side addiction is low.\textsuperscript{16} A reason for this is that patients do not dare to use illegal drugs because the consequences of the violation are so severe. In addition, the programmes get rid of troublesome patients, so that these may not modify the statistics in a negative direction. The consequences for those excluded are harsh. Mortality is high. Survivors will return to intense opioid abuse, some mostly sticking to heroin, while others are trying to create their own maintenance programmes by buying methadone or buprenorphine on the black market. Many are forced to resort to crime to make ends meet. Consistently, the patients’ living conditions are impaired, as well as their contacts with family members and their physical and mental health. That patients are also excluded from any maintenance treatment for at least three months means that they cannot apply to other maintenance programmes, which is what other patients can do if they find themselves in conflict with their healthcare providers.

**Limitations**

Most participants in our study were either patients at the Infection Clinic or the Ad-
diction Clinic. A consequence is that we have not had contact with people who are entirely medication-free, except from one diagnosed with hepatitis C. The conclusions do not therefore apply to that group. However, our view (supported by other research) is that it is rare for people to remain medication-free after an involuntary discharge.

This study has focused on patients’ versions of being discharged and on the consequences the discharge has had. People who describe a conflict situation have an interest to be seen as sensible and righteous, which means that their story should not be regarded as impartial descriptions of a course of events (see Hedin & Månsson 1998). In addition, their last discharge is, on average, 30 months in the past. There is thus a risk of memory failure. However, as the sociologist W.I. Thomas says in his famous theorem of 1928: “If men define situations as real, they are real in their consequences.” Discharge, then, becomes real through the ways in which the patients see themselves in relation to the treatment system and how they convey the discharge to friends and acquaintances. Biased or not, this is why their stories are important to get out in the open.

Declaration of Interest None.

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NOTES
1 The NBHW is the Swedish authority tasked with ensuring that health and social services are of high quality and are delivered in accordance with scientific criteria and clinical experience (Socialstyrelsen 2011, 1). The Board is therefore responsible for the legal framework regulating maintenance treatment.
2 There are no current figures on how many heroin users have received non-medication treatment in Sweden, but this form of treatment has probably declined during the 2000s.
3 Dropout is a collective term for all types of discontinuation of treatment, both those initiated by the patient and by the programme. This study deals only with patients who are involuntarily forced to leave the programme.
4 Between 2005 and 2009, the time limit was set to 6 months. Before 2005, it was a year for methadone, but in practice usually much longer because the patient was also placed at the end of the waiting list. For buprenorphine, there used to be no time regulations but they were introduced when the NBHW established a common framework for all maintenance treatment in 2005.
5 Over the past three years the number of involuntary discharged patients has declined because MAT programmes in Malmö have chosen to apply the regulatory system less rigidly. Whether this change is permanent, or whether the rules will again be more severely interpreted cannot be predicted at the time of writing.
6 In addition, professor Mats Berglund, MD
Anders Håkansson, social worker Camilla Wallin and doctoral student Torkel Richert participated in the organisation of the survey. The study was funded by Mobilisation Against Drugs. The project has been reviewed by the Regional Ethical Review Board in Lund.

7 A comprehensive study of European opiate users reported an average delay of about 10 years between first use of opiates and first treatment contact (EMCDDA 2010).

8 According to a summary of the Methadone Register 1989–2004 by the NBHW, a total of 1,459 discharges of 1,027 people were carried out. Side abuse was the stated reason in 40% of the cases, whereas discovered crime accounted for 9.7% of the involuntary discharges, and other causes for 18.8% of the cases, amounting to a total of 68.5% being involuntarily discharged. Only 7.6% had voluntarily left their treatment, while 12.5% had been transferred to another programme. For 150 patients (14.6%), the indicated discharge cause was death (National Board of Health and Welfare 2006).

9 In a summary from the years 2008–2010 that the Addiction Clinic made for us, side abuse was the most important reason for discharge (26 of 67 involuntarily discharged), followed by absence for more than a week (21 individuals) (Bråbäck 2011).

10 It takes 35 minutes by train from the city of Malmö to Copenhagen, Denmark.

11 One possible explanation for the high percentage of women returning to MAT is the start in 2006 of Navet, a special clinic for women, with the aim to open a VIP lane into treatment (Laanemets 2007).

12 Primo is one of the main characters in Bourgois’ ethnographic book ‘In Search of Respect’, a creative and successful entrepreneur dealing in cocaine. But later, he goes on to heroin, which causes him to lose control of his addiction.

13 Although methadone is addictive, almost 50% leave treatment in the first year (Kelly 2011), indicating that Bourgois’ concern about methadone’s disciplining effect may be somewhat exaggerated.

14 In an international comparison, the Swedish methadone programme uses relatively high doses, giving rise to a long withdrawal period (SBU 2009; Stålenkrantz 2010). In 2008, in the Stockholm Programme, the average dose was 90 mg (Davstad 2010). Doses above 80 mg count as high (Strain et al. 1999).

15 The softening has taken place without a change in the NBHW rules, showing that there is some leeway, which was not used in Malmö during the period under investigation.

16 Outside Sweden, side abuse of heroin, cocaine, cannabis, etc. is seen as almost natural during maintenance treatment. The goal is to minimise this, but side abuse alone is not usually a reason for discharge.


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