



Patients' Perspectives on Coming Off Opioid Agonist Treatment: A Qualitative Study

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ABSTRACT

AIMS: Opioid agonist treatment (OAT) programs are life-saving, as they reduce opioid use, overdoses, and criminal activities. Disadvantages reported with long-term OAT include side effects of the medication, especially on cognitive ability and sexual function, which may discourage potential participants. Many of those who participate in OAT have a desire to come off treatment. The aims of this study were to explore patients' thoughts about coming off OAT and to investigate their perceptions of what support they would need in order to realize a planned withdrawal from OAT.

METHODS: A qualitative interview study with semi-structured interviews, using applied thematic analysis. Persons with experiences of participating in OAT were invited from Swedish programs and a private Facebook community.

RESULTS: Fifteen persons, with a mean of 9.6 (± 6.4) years of treatment experience, were included. The participants underlined the need for a patient-centered focus within the treatment. They wanted to be regarded as capable of deciding if, when, and how a planned ending was to take place. They also called for staff to be supportive in making such decisions. Participants recommended staff to be sensitive to the needs of the specific patient and to have strategies for coming off OAT that could be adjusted for the single person.

CONCLUSIONS: OAT programs need to be continually updated and adapted to the persons who can benefit from them. Applying a person-centered, holistic perspective would enhance the quality of the treatment by emanating from individual goals. Regulatory guidelines need to take into account research on patient experiences and perspectives on coming off.

KEYWORDS: Opioid agonist treatment, medication for opioid use disorder, patients' perspective, qualitative, treatment length, coming off treatment, thematic analysis

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Introduction

Treatment of opioid use disorder (OUD) using pharmacotherapy was first introduced in the early 1960s. American physicians Dole et al¹ presented a treatment program in which methadone was used to block craving and minimize withdrawal effects in persons with heroin addiction. In doing so, they broke with a tradition of seeing addiction as a result of an intractable moral defect. Dole and Nyswander² framed heroin addiction as a metabolic or "psychopharmacological" disease but emphasized the need for social support to strengthen rehabilitation. Still today, opioid agonist treatment (OAT) programs, by definition, include social and psychological services.³

Addiction to heroin and other opioids remains an important and persistent health and social problem worldwide.^{4,5} Three high-income regions in the world have a particularly high prevalence: Australasia, Western Europe, and North America. The "opioid epidemic" in the USA has now reached a level at which it is considered a serious public health concern, causing a reduction in life expectancy.⁶ In other parts of the world a similar epidemic has not been seen but the number of persons with OUD is still at a level that calls for

societal concern.^{5,7} In Sweden, the estimated non-prescribed use of opioids is on a medium level in comparison with other European countries.⁸

OAT programs are life-saving, as they reduce opioid use and unwanted effects that accompany it, such as overdoses, HIV infection, and criminal activities.^{9–12} Still, OAT is not attractive to all persons with OUD. Disadvantages reported with long-term OAT include side effects of the medication, especially on cognitive ability and sexual function.¹³ Taking part in OAT has also been described as a feeling of being "stuck in limbo," an intermediate state between recovery and a continued life with addiction.^{14,15} Importantly, many potential participants perceive the treatment as life-long and requiring continuous contact with healthcare, which can be seen as an infringement on personal integrity. From long-term clinical experience, we are cognizant that people who could benefit from such treatment are well aware of its downsides. It is estimated that only between 20% (USA) and 50% (Europe) of people with OUD receive OAT.¹⁶ Low participation rates may be due to a number of reasons other than personal beliefs, such as low availability in some areas and, particularly in the USA, insurance coverage.



Over the 60 years since the introduction of OAT, different standpoints have developed over the issue of treatment length.¹⁷ Some argue that patients with OUD—like patients with diabetes or other comparable conditions—should maintain life-long treatment.¹⁷ For others, the ultimate goal is to assist the patient to withdraw from OAT and lead a drug-free life.^{17,18} Countries differ in their treatment policy concerning the purpose and length of OAT. In the United States, national authorities advocate for abstinence as a goal for OAT.¹⁹ The European Union Agenda and Action Plan on Drugs focuses on harm minimization rather than abstinence-oriented approaches,²⁰ but many countries in the EU have nation-specific guidelines. In the United Kingdom, the emphasis is placed on treatment exit and recovery in terms of abstinence.²¹ In Sweden, leaving OAT is recommended primarily as a response to the patient's wish to do so.²² In practice, treatment goals may vary considerably across and within countries and over time.

Many who participate in OAT have a desire to come off the treatment.^{23,24} In one study, 62% of patients expressed a strong interest to end treatment within the next 6 months, and 15% were quite interested. Only 12% stated that they were not at all interested in coming off the treatment.²⁴ Similar proportions have been found in other studies.²⁵ Researchers in the UK reported that only less than 10% of people who enter OAT leave the program abstinent.^{21,25} Others have pointed out that many leave treatment unplanned, and only between 30% and 50% of those who started treatment remained after 6 months.²⁴ The retention rate varies widely across programs.²⁶ Unplanned discontinuation of treatment increases mortality risk substantially.²⁷

The number of OAT programs is growing, and programs accept younger persons more than before—in Sweden, now from age 18.²² Hence, there is a need for greater knowledge on suitable ways of using OAT for only a period in life. OAT might be more attractive and thus life-saving if perceived as an available treatment even for those who just want it for a limited time. Recent studies in which people who have undergone OAT express their thoughts specifically on coming off treatment are rare,²⁸ although there are numerous studies on their experiences and perspectives of OAT in general.^{21,23,29}

The aim of this study was to explore patients' thoughts about coming off OAT and to investigate their perceptions of what support they would need in order to realize a planned withdrawal from OAT.

Methods

This study was explorative and descriptive. Using a qualitative research methodology provides insight into the experiences and perceptions of persons who consider leaving OAT, which is particularly useful when the area of interest is sparsely studied.³⁰

Setting

Historically, in Sweden, OAT has been subject to strict regulations, involving highly specified standards for treatment

admission, drug testing, and discharge from treatment.³¹ For example, up until 2016, persons with OUD could only be included if a specialist in psychiatry certified that the disorder had existed for at least 12 months prior to entry. Patients who did not follow their individual treatment plan were likely to be dismissed.³² Since 2016, regulations are less prescriptive and leave more room for the physician in charge to decide whether the program will benefit the person seeking treatment. An individual treatment plan must be established, including dosage, voluntary group or individual therapy, and social support if needed.³¹ The distribution of patients receiving methadone or buprenorphine is about 50/50 in Sweden.³² Programs are mainly organized within the public health care system, but they can also be commissioned to privately-run caregivers who get funding per patient, which, in turn, may mean a risk for a lack of an incentive to end treatment.

Recruitment

Participants were recruited from OAT programs across Sweden and from a private Facebook community for people participating in OAT. An information letter about the study was distributed to key persons within the programs, who, in turn, forwarded it to potential participants. The information letter, explaining the study's focus on coming off the treatment, was posted in waiting rooms, and it was also published in the private Facebook community. The letter welcomed any participant with at least 1 year's experience of the treatment to join. We deemed 1 year was minimum for a person in OAT to become fully acquainted with and accustomed to the program. The researchers were contacted by potential participants via text message or e-mail. Those who contacted the researchers were sent written information about the study and were invited to make new contact if they wanted to participate. Oral information was given, and consent was obtained from all participants. Ethical approval was obtained from the Swedish Ethical Review Authority (Dnr 2020-00541).

Data collection

An interview guide was developed by the authors, built on clinical experience. After a pilot test with 2 participants only minor changes were made, and the 2 interviews were later included in the analysis. All interviews were conducted by telephone, which is considered to give as rich data as face-to-face interviews.³³ Each interview was recorded on Mp3-players and transcribed verbatim. The interview sessions ranged from 15:29 to 36:05 minutes long, with a median length of 24:31 minutes.

Semi-structured interviews with open-ended questions were used to capture the participants' perceptions, experiences, and feelings.³⁴ Participants were asked to describe their thoughts about coming off the treatment, what they found valuable and important about OAT, and specify any negative

Table 1. Demographic description of the participants.

PARTICIPANT NUMBER	GENDER	AGE	YEARS IN OAT	OCCUPATIONAL STATUS
1	Female	56	24	Working
2	Male	37	3	Working
3	Male	27	8	Unemployed
4	Male	45	7	Working
5	Female	62	15	Working
6	Female	39	6	Working
7	Female	Not available	12	Sick-leave
8	Female	34	1	Self-employed
9	Male	47	15	Working
10	Male	28	4	Working
11	Female	23	2	Parental leave
12	Male	47	14	Unemployed
13	Female	46	10 α (6) β	Working
14	Male	61	16 α (11) β	Voluntary worker
15	Male	37	7 α (8 mo) β	Unemployed

α Has tapered off and left OAT.

β () Time passed since leaving OAT.

aspects of OAT. They were also asked how health care services could be supportive for those who want to leave OAT.

Interviews were conducted by authors CN and CWB, both trained in interviewing techniques and with 20 to 25 years of experience in working within substance use disorder (SUD) treatment and psychiatric care. All authors have extensive experience in SUD health care, other psychiatric care, or both.

Data analysis

The interview data were analyzed using applied thematic analysis.³⁵ Applied thematic analysis draws from a broad range of several theoretical and methodological perspectives. Its primary concern is with presenting the participants' thoughts and experiences as accurately and comprehensively as possible. Themes were identified and analyzed inductively, that is, themes were formed from data only and not from predetermined hypotheses. Once 15 interviews had been conducted, information from the last ones did not produce any changes to the themes. Thus, we deemed that saturation was achieved.^{36,37}

The transcripts were read several times independently by all authors. Meaning units—words and sentences of interest in line with the aims of the study—were coded. After joint discussions with all authors, the codes were sorted into preliminary themes. The material was re-read, and the themes were reviewed, and sub-themes created. The analysis continued until all themes were deemed to be clearly defined and distinct from

one another. All authors discussed the coding of the data until a consensus was reached, and themes were perceived as concisely describing the content.

Results

In all, 17 persons contacted the research team via text message or e-mail. Of those, 15 were available for an interview and willing to participate. They were 8 males and 7 females, with a mean age of 42.2 (± 11.5) years, range 23 to 62. Their mean number of years in OAT was 9.6 (± 6.4), range 1 to 24 years. The participants had experiences from OAT programs in 14 different cities all over Sweden. For further presentation, please see Table 1.

In the analysis, 3 themes were identified: (1) *The initial phase*, (2) *A strive for independence*, and (3) *Ways out of OAT*. The themes and their subthemes are presented below with verbatim quotes to illustrate the findings.

Theme: *The initial phase*

A massive change. The participants explained how their wish to come off OAT depended on what treatment phase they were in. They described the initial phase, about 1 to 2 years, of treatment as a period in which they experienced powerful, positive changes in their lives. Thanks to the medication, cravings were avoided, and a new life could begin without a desperate struggle to maintain the supply of opioids. Some participants

described OAT as life-saving; others stressed how they had been given new possibilities in life. They did not express any thoughts about leaving the program in this phase.

I was in residential treatment a few times. But it failed again and again. And when I got the chance to take part in OAT, it was just like switching a button. It was such a massive change at once. (#9)

Many participants appreciated how OAT made it possible for them to break free from their previous life.

I just think. . . How different from lying abstinent in a caravan, getting out and starting working, getting a home, getting a career, a meaningful job, and getting a good life with friends, family, travel and international contacts. All that would have been impossible if I hadn't been able to participate in OAT. (#5)

Structure and care. In the initial phase, the programs also helped to create a structure in participants' life, much-needed routines to follow, and an opportunity to meet with empathetic staff members whom the participants could trust. Regular drug tests motivated some to refrain from the side-use of illicit drugs, and others described a feeling of being in good medical hands. They felt the program was a place they could turn to if they needed medical attention or social help.

In my heart, I will always keep that first contact person I had there. The first months, she helped me survive. (. . .) In the beginning, I felt good about getting up in the morning and going to the program facility and meeting my contact person. And once, I invited her home to my place, where we had lunch. I really appreciated that person. (#5)

Theme: A strive for independence

To feel locked up. All participants, except one person who had joined the program only 14 months earlier, had presently or at some point had a wish to end treatment. They described wanting to liberate themselves from their dependence on the medication and the controlled life within OAT. Vigorous terms like "a chemical leg iron," being "tied up," or "locked up in every way" were used.

*Over time, I have come to feel it's like a chemical leg iron. You're tied to that - sorry - f***ing clinic. You have to go there, and every week you have to go and get your medication. (#4)*

Being under medication kept participants from traveling abroad because they were not trusted with sufficient amounts of the medication and might be questioned by the customs officers.

I made the decision [to come off] partly because I enjoy travelling. (. . .) It would be much more convenient if I didn't have something I had to take. It is more difficult to make plans if you want to stay away for a couple of weeks. (#9)

Some felt it was difficult to lead a working life while they had to collect their medication within limited program opening hours.

Let's say you relapse, and you have to go to work. You have to go and get your dose every morning. But you have to be at work at 7 [am]. Then it's not easy to keep a job, or to get one. (#10)

On numerous occasions, the participants brought up the environment at the treatment center as a factor that made them feel locked up in an identity they wanted to move away from. In the waiting room, they had to face unwanted contacts and drug dealing.

I feel I want to quit also because I can't stand meeting addicts all the time. It's not good. I don't get on with my life. (#12)

A wish to live unaffected by drugs. Side effects of the medication, such as tiredness, drowsiness, and sweating were brought up as reasons for considering leaving the program. Disturbances in their sex life were also reported.

I go to bed every night at 7.30 (. . .) You lose that fire inside you. That's what's negative, and that's why I want to quit now. Because I want a functioning sex life. I want that fire and spark back. (#2)

I got more and more troubled by side effects. If it wasn't for the side effects, I probably would have continued [with OAT]. Now that I'm off, I feel better. I don't sweat, I don't get formications [stinging sensations]. It's very nice to wake up in the morning and not feel any formications. Or in the middle of the night. (#15)

An unbalanced relation with staff. One particular aspect that participants often raised was their non-balanced relationship with their caregivers. They had to adhere to rules set by others, and they were dependent on the person who prescribed their medication. Consequently, a change of staff could be a potential threat to their current existence.

It could simply be a new consultant who decides 'No, we can't have patients here that we don't control every week, or who we give this much responsibility.' That would leave me in a situation where I would risk losing everything that I have built up. And I don't want to hang on that hook anymore. (#5)

Some participants felt they were under surveillance and not regarded as trustworthy. Contacts with staff were sometimes described as merely a control mechanism.

I need help for my background anxiety problems. (. . .) But the only thing they offer is antidepressants. I have been offered the whole list of them. (. . .) They focus too much on medication, and that is the wrong focus. There is so much focus on medication, rather than on the underlying problems or that you need to get on with your life. (. . .) I feel as if they are in total control of my life. (#6)

A few participants had a wish to come off the treatment which was not supported by the program staff.

They always told me 'You're going to have this for the rest of your life.' And when I decided to quit, they said I was never going to make it.

(. . .) But I felt 'damn, I'm going to show them.' I knew they had no right to stop me from quitting. (#14)

Many participants mentioned the risk of getting expelled from the program because of a relapse.

I know how sick I will get. I would have quit long ago if I could. But I am scared to death about losing my maintenance treatment. (#12)

Theme: Ways out of OAT

The participants had several recommendations for the health care staff on the issue of coming off OAT. One reoccurring recommendation was to investigate the patient's attitude to treatment length, not only at the beginning of the treatment but also continuously. Bringing up the issue of patient's attitude continuously should be a routine that is presented upon the start of the treatment. They also suggested that staff members should present viable alternatives, in which the patient could control the speed of change.

That's something they bring up at the first meeting, but then they never follow it up. It only comes up again if I bring it up myself. They always seem to find some reason why it's not a good idea. I have never gotten to hear 'This is what you can do, these are the alternatives. . .' It's only about plans I have come up with myself. (#6)

Participants stressed the need to be sensitive to the patient's signals and bring up the possibility of coming off the treatment when there is a window of opportunity. On the other hand, some participants advised against staff-initiated discussions related to leaving the treatment. They felt that such advice could provoke feelings of submission and opposition.

Participants recurrently underlined the need to feel in control of the speed of the detoxification and the need to feel sure that they would not be expelled if they failed.

One mustn't feel a pressure from program staff to quit, you should make your own decision. And that's how it's been: every lowering of the dose has been on my initiative. And beyond that I have also demanded a guarantee, that if you step off and it doesn't work, that you can return immediately. Without having to be referred to a waiting list for months or more. Because if you should get that feeling that it is not going to work, then it might get very critical to get back into safety again. (#9)

One participant pointed out that staff could stimulate people to try to come off OAT by emphasizing and supporting patient control.

If you made the patients feel more in control of the treatment, if you could make them less exposed to arbitrariness and predomination and such, then people may dare to try [to stop]. Because if you feel insecure, you cling to what you've got. Because you know you can lose it. But if it's not that way, who knows what can happen? (#5)

Some feared that they would be left alone if they managed to taper off, and called for prolonged care after detoxification.

Once you have tapered out, that's when the hard part begins. But at that time, they are not responsible for you anymore. (. . .) There must simply be a program for those who want to leave. Something with at least a streak of science in it. (#12)

Discussion

In this study, persons with experience of OAT were able to express their thoughts and views on the prospect of leaving the treatment in their own words. To our knowledge, this is the first study to use interviews to investigate this area. The participants highlighted the need for a patient-centered focus. They wanted to be regarded as capable of deciding if, when, and how a planned ending of the treatment was to take place. They called for staff to be supportive in making such decisions. Thoughts about leaving the program also caused fear of what might happen without OAT. One concern was that they could be expelled from the program if the detox failed, and not be welcomed back.

The participants expressed strong, and sometimes opposing, feelings about the impact of the treatment and the staff on their daily life. On the one hand, they felt fortunate to have gotten the chance to get a life without illegal opioids. The pharmacotherapy and the structure of daily life and supportive contacts with staff were some of the constructive features of OAT. Over time, the positive features of the program changed into feelings of lost control and submission. To secure what they required to maintain their new life, the participants had to submit to rules that included an amount of control, such as urine drug monitoring, daily visits to the treatment center, and exposure to staff change, which hampered their ambitions to lead a "normal" life. In previous interview studies, participants described their mixed feelings in similar terms.^{15,23}

The interviews also illustrate that program staff might underestimate OAT participants' will and ability to leave, as observed in previous studies.^{28,38} Many participants reported that the staff had raised the possibility of quitting OAT at the start of treatment but rarely later in the program. Some also expressed that the staff were reluctant or even negative about the process of tapering off treatment. This stance may be due to a concern for the patient or a lack of trust. Already in the 1980s, participants sought better support from staff in their wish to detoxify.²⁸ There are also results that highlight a lack of correspondence between program measures of outcome and patients' descriptions of the goals of treatment.^{39,40} Patient-centered or person-centered care, where patients are a part of the treatment decision-making, has been advocated in substance abuse treatment⁴¹⁻⁴⁴ and in OAT.⁴⁵ However, there are indications that clinics serving patients in OAT are less likely to use person-centered care than health care in general.⁴⁶⁻⁴⁸ Recent studies have reported a lack of patient input into treatment decisions in OAT, which makes the patients feel under the control of the health care authority, rather than in own control.⁴⁹ This, in turn, may create conditions for poor outcomes with OAT. To reduce the stigma and optimize treatment, it is crucial to take

patients' experiences into consideration.^{44,48,50} Participants in our study highlighted the importance of being treated with respect for individuality. They described that it was necessary to feel in control of their treatment if they were to be able to take steps forward. In person-centered care within OAT, treatment plans should always include assessment of each person's perspective and hopes for their future.

In their recommendations to health care on how a planned ending can be realized, participants again stressed the need for a focus on the person. Staff should be sensitive to the needs of the specific patient and have strategies for those interested in coming off treatment—strategies that could be personalized. Some programs allow patients to stay in the program for up to 1 year after detoxing, while they receive other types of support such as voluntary drug tests or psychological treatment.⁵¹

Strengths and limitations

With an invitation to eligible study participants, clearly describing the study focus on their thoughts about coming off OAT, the included informants were able to share rich descriptions of their experiences in the interviews.

Studies on patients' encounters with OAT programs have mainly been conducted in English-speaking countries. Our study contributes new findings from Northern Europe on a subject, the potential to come off OAT, that is rarely raised. Thus, our study broadens the discussion on further development of OAT programs.

The participants in this study gave examples of varying experiences regarding time spent in OAT. There was also a wide age span. These variations, together with differences in occupation status, are a strength of the study.

To strengthen trustworthiness, the members of the research group, with extensive experience in addiction- and psychiatric care as well as qualitative research, were all involved in the analysis.

This study, along with qualitative studies in general, included a relatively small sample. Rather than seeking generalizability, the aim was to identify different types of factors of importance. By the description of methods, setting, and participants, the reader can decide about the transferability of the findings to other settings.

Conclusions and implications

Participants in this study expressed how the experience of a life-saving support from the program was, over time, shifted toward a wish to become independent and to go on with life in a new direction. They made a strong call for a focus on their individual needs and wanted to be treated as capable of deciding if, when, and how a planned ending of the treatment was to take place. Participants also called for the staff to be supportive in making such decisions.

The participants had several recommendations to staff and administrators on how a planned ending of OAT could be realized. Those suggestions underlined the need for a

person-centered focus. Applying a person-centered, holistic perspective would enhance the quality of treatment by emanating from individual health needs and goals. To achieve this in practice, regulatory guidelines need to take into account research on patient experiences and perspectives on coming off.

In future studies, methods to support persons who wish to come off OAT could be developed and examined. For example, such efforts may include peer support and mentoring.⁵² Staff attitudes regarding treatment length may also be of importance when handling termination of OAT and is an area our research group is currently investing.

Author contributions

CN conceptualized the project. CN and CWB performed the interviews. All authors took part in analysis and interpretation of data. CN wrote the original draft of the manuscript. All authors were involved in reviewing and editing the manuscript.

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