BMJ Open Patients' perspectives on tapering programmes for prescription opioid use disorder: a qualitative study

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ABSTRACT

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Lisa Eveline Maria Davies; I.e.m.davies@uu.nl **Objectives** Approximately 10% of chronic pain patients who receive opioids develop an opioid use disorder (OUD). Tapering programmes for these patients show high drop-out rates. Insight into chronic pain patients' experiences with tapering programmes for prescription OUD could help improve such programmes. Therefore, we investigated the perspectives of chronic pain patients with prescription OUD to identify facilitators and barriers to initiate and complete a specialised OUD tapering programme. **Design** A qualitative study using semi-structured interviews on experiences with initiation and completion of opioid tapering was audio recorded, transcribed and subject to directed content analysis.

Setting This study was conducted in two facilities with specialised opioid tapering programmes in the Netherlands.

Participants Twenty-five adults with chronic pain undergoing treatment for prescription OUD participated. **Results** Participants indicated that tapering is a personal process, where willingness and motivation to taper, perceived (medical) support and pain coping strategies have an impact on the tapering outcome. The opportunity to join a medical-assisted tapering programme, shared decision-making regarding tapering pace, tapering location, and receiving medical and psychological support facilitated completion of an opioid tapering programme. Conclusions According to patients, a successful treatment of prescription OUD requires a patient-centred approach that combines personal treatment goals with shared decision-making on opioid tapering. Referral to a specialised tapering programme that incorporates opioid rotation, non-judgmental attitudes, and psychological support can create a safe and supportive environment. fostering successful tapering and recovery.

INTRODUCTION

The use of prescription opioids has increased substantially worldwide in the past decades.^{1–5} Despite the lack of evidence of long-term effectiveness, opioids are often prescribed for chronic non-malignant pain.^{6 7} Meanwhile, growing evidence shows that treatment of chronic pain (CP) with opioids can result in severe side effects, which increase dose-dependently.^{8 9} Up to almost one-third of CP

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ Selection of chronic pain participants who tapered their opioids after rotation to buprenorphine or methadone in a specialised programme.
- ⇒ In-depth qualitative study to gain a comprehensive understanding of patient's experiences with tapering.
- \Rightarrow Rigorous data saturation within a diverse study sample.
- ⇒ Potential recall bias when asking about past experiences.

patients (21%–29%) misuse their opioids, and approximately 10% develop an opioid use disorder (OUD),¹⁰ ¹¹ characterised by prolonged use of opioids causing clinically significant distress or impairment.¹² Therefore, CP patients with long-term prescription opioid use (eg longer than 90 days) are advised to taper their opioids.¹³

Although opioid prescriptions are frequently introduced first in secondary care, opioid tapering is often initiated in primary care.¹⁴ However, for CP patients, tapering opioids can be challenging due to the fear of worsening pain, withdrawal symptoms and deterioration of their functioning.14-19 Drop-out rates (not fulfilling withdrawal) during prescription opioid-tapering attempts are high, so understanding which factors facilitate and complicate tapering is essential.^{20–22} These studies mention that screening for depressive symptoms and pain intensity during withdrawal, the overall treatment duration and medication-assisted tapering facilitated increased completion rates.

Hence, the current guidelines suggest that for patients with psychiatric comorbidity or severe addiction problems, referral to specialised opioid tapering programmes should be considered.²³ This may also account for patients with failed previous tapering attempts in primary care. However, the lack of studies on inpatient treatment or specialised tapering programmes for this specific patient group highlights the need for further research to explore successful interventions that can support their recovery journey. So, understanding CP patients' experiences with referral programmes for prescription OUD and gathering input from patients to assess the most pressing issues regarding treatment retainment are crucial to improve care access and success rates in tapering.

Therefore, this study aims to investigate CP patients' views on opioid tapering, including barriers and facilitators for initiating and completing a specialised prescription OUD tapering programme.

METHODS

Study design

A qualitative study using in-depth, semistructured interviews with CP patients and prescription OUD was conducted.

Setting and participants

Participants were purposively recruited from two facilities with specialised opioid tapering programmes in the Netherlands: (1) the Department of Psychiatry of Radboud University Medical Centre (Radboudumc) in Nijmegen, specialised in addiction psychiatry, and (2) Novadic-Kentron in Vught, a specialised addiction care facility with a programme for CP patients, between November 2020 and July 2021. Both programmes provide opioid rotation, detoxification and therapy to improve pain coping strategies (eg, cognitive behavioural therapy (CBT), mindfulness-based treatment, education on pain and the use of painkillers, acceptance and commitment therapy, and graded activity). To be eligible for the study, patients must be proficient in Dutch, 18 years or older and considered stable enough to participate, have a chronic pain condition and be classified with OUD by a trained physician or psychologist in a structured clinical interview (eg, Measurement for Addictions and Triage (MATE) based on the DSM- 5^{24}).

Participants were informed about the study by their treating healthcare professional. If patients agreed to participate, one researcher (LEMD) provided a detailed explanation of the study procedures via telephone and set an appointment for a 1-hour interview. Due to COVID restrictions, all interviews were performed via telephone or video call. Participants did not receive a financial incentive for participation. Recruitment continued until thematic data saturation was reached.²⁵ At that point, three additional interviews were planned as a final measure to ensure data saturation.

Patient and public involvement

Patients were not directly involved in the study's design, conduct or management. This study, however, takes place within the Tackling and Preventing the Opioid Epidemic (TAPTOE) consortium. This consortium has an advisory board that includes patient representatives and healthcare professionals, and provides general inputs on study designs, conduct and management, and dissemination of the study results to the public.

Data collection

The interview guide was based on topics included in the Prescription Drug Use Questionnaire (PDUQ)²⁶ and composed of broad, open-ended questions aiming to elicit perceptions and experiences regarding long-term opioid use and tapering. The interview guide was iteratively refined after two interviews to ensure that all relevant themes were addressed (online supplemental materials). Interviews were conducted by one female researcher (LEMD), a PhD candidate who has a Master's in Epidemiology and followed multiple qualitative research courses including interview skills. Another female researcher (VWTvD), a master's student in pharmacy who followed patient communication education, participated in the first four interviews. The researchers had no personal interest in the subject, apart from the fact that this is the subject of their PhD and master's thesis. No relationship was established with participants prior to the study.

All interviews were audio-recorded. The following patient characteristics were extracted from the medical records: opioids used at clinical admission (name and dosage), comedication, type of chronic pain and comorbidities (both physical and psychiatric).

Data analysis

Interviews were transcribed verbatim, and field notes were incorporated into the transcripts. Transcripts were not returned to the participants for comment. Directed content analysis was used to determine the presence of themes using a predefined coding tree based on the interview guide and literature regarding opioid tapering experiences.14 15 20 27 New codes were created for additional themes identified during the analysis. The final coding tree was applied to all transcripts and can be found in the online supplemental materials. Two researchers (LEMD and VWTvD) coded the first four transcripts, and then one researcher continued coding (LEMD). All added new codes were discussed with another researcher (ESK). Concept categories and themes were identified based on the codes, which were regularly evaluated with the research team for consistency. The participants did not provide feedback on the findings. Nvivo 12 was used for data management and analysis, and the findings were reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ).²⁸

Ethics and confidentiality

The medical ethical review committee of Radboudumc declared that the study was not subjective to the Dutch Medical Research Involving Human Subjects Act (WMO) (2020–7037). All procedures were approved by Utrecht University Institutional Review Board (division of Pharma-coepidemiology and Clinical Pharmacology (UPF2018)).

Before the start of the interview oral informed consent was obtained from all study participants. Identifying references to names, locations and institutes were anonymised in all transcripts.

RESULTS

A total of 25 interviews were conducted, of which 17 interviews were conducted via video call (68%) and others via telephone. Data saturation was initially achieved after 17 interviews at Radboudumc, after which three more were conducted. Two additional interviews at Novadic-Kentron did not yield new themes, leading to the final three interviews. All recruited respondents participated in the study. On average, the participants were 53 years old, and 52% were female. More than half of the participants used opioids for at least 5 years. Most patients used oxycodone (80%), either as monotherapy or in combination with other opioids (table 1 - Participant characteristics and online supplemental table 1 - Detailed participant description). Eighteen participants had undergone at least one previous tapering attempt (72%). Two participants did not complete the opioid rotation. Identified barriers and facilitators related to initiation of opioid tapering and successful completion of opioid tapering are depicted in figure 1. The main themes are discussed in more detail below.

Barriers for initiating opioid tapering

Fear of increasing pain and past experiences with withdrawal symptoms

Many participants indicated they wanted to taper but feared increasing pain and losing their ability to manage their pain with opioids. Past negative experiences with tapering also made them hesitant to try again, and the absence of alternative medical pain therapy from their treating physicians worsened their concerns and discouraged seeking treatment for their OUD.

The answer I got from most doctors was: 'I wouldn't know what else to give you for the pain. I can give you some extra, but I cannot remove the fentanyl and give you another medicine that treats your pain. (P6, male, 60s)

Perceived lack of (medical) support

Some participants wanted to discuss tapering or alternative pain medications but felt that their healthcare provider was reluctant to discontinue their opioid treatment. They felt stigmatised and unsupported instead of receiving assistance with their opioid tapering treatment plan.

They send you home saying: 'You have an addiction and we do not treat this at the hospital'. All doors were closed for me from that moment on. (P25, female, 40s)

Table 1 Participant characteristics	
Participant characteristics (total n=25)	
Gender, n (%)	
Female	13 (52%)
Age, mean (SD)	53 (±10)
Type of chronic pain indication to start opioid treatment, n (%)	
Chronic visceral pain	2 (8%)
Chronic musculoskeletal pain	10 (40%)
Chronic neuropathic pain	5 (20%)
Chronic postsurgical and posttraumatic pain	6 (24%)
Chronic widespread pain	2 (8%)
Patient-identified duration of opioid use, n (%)	
≤ 5 years	9 (36%)
>5 years	14 (56%)
Unknown	2 (8%)
Information collected at admittance in facility	
Average daily OME at intake, mean (SD)	254±384 mg
Opioids used, n (%)	
Tramadol	1 (4%)
Oxycodone	9 (36%)
Fentanyl	5 (20%)
Combinations	10 (40%)
Other medication, n (%)	
Antidepressants	14 (56%)
SSRI	6 (24%)
TCA	8 (32%)
Antipsychotics	5 (20%)
Benzodiazepines	10 (40%)
Gabapentinoids	8 (32%)
Other painkillers	10 (40%)
Completed rotation at facility, n (%)	23 (92%)
Opioid rotation medication, n (%)	
Buprenorphine/naloxone	20 (80%)
Methadone	4 (16%)
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OME, Oral Morphine Equivalent; SSRI, Selective Serotonin Reuptake Inhibitor; TCA, Tricyclic Antidepressant.

Buprenorphine

Participants could not find professional support for tapering and were often referred to addiction clinics without prescription opioid tapering programmes. This resulted in feeling stigmatised and being referred to as 'addicts', discouraging them to initiate tapering. Additionally, long waiting lists for inpatient treatment further demotivated them.

I have tried so long to find someone to help me taper. I called multiple clinics, but they were not equipped

1 (4%)

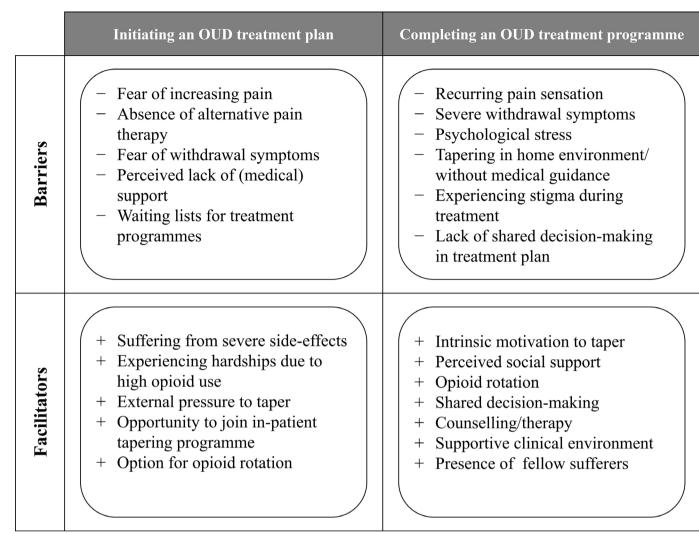


Figure 1 Barriers and facilitators to initiate and complete an OUD treatment programme.

to deal with prescription opioids. I would be housed with illicit drug users, I don't feel like being grouped with the homeless and drug addicts. (P20, female, 50s)

Furthermore, some participants specifically mentioned the effect of negative tapering stories on social media.

You want to quit, but there are horror stories all around (on social media), so I didn't dare try to stop! (P25, female, 40s)

Facilitators for initiating opioid tapering

Suffering from negative side effects

Most participants experienced escalating side effects that outweighed the benefits of opioid use, including dependency, irritability, apathy, hyperalgesia and memory loss, which significantly impacted their quality of life. In some cases, severe opioid use led to extreme hardships, such as accidents or using more than a palliative family member, which confronted them with the gravity of their opioid dependence, compelling them to proactively consider and initiate opioid tapering. It is a sum of multiple factors coming together, resulting in a realisation: Something has to change, this can't continue like this, I need to quit. (P10, male, 50s)

External pressure

In some cases, participants started tapering in order to qualify for the therapy they were excluded from due to high opioid dosage. Having a goal and a prospect of a better future was crucial in the initial phase, and support from family, friends or healthcare providers was helpful. Although the negative effects of continuous opioid use were apparent, the response of their direct environment was considered a major trigger to actually start tapering.

Over 3 to 4 years my personality changed a lot. I wasn't myself anymore ... I was negative and depressed ... I kept noticing more negative effects of oxycodone, so that had to go. But at that time, I was unaware. Thankfully my parents were always supportive. They raised the alarm and informed me that I needed to change. (P8, male, 40s)

6

Opportunity for inpatient tapering programme with opioid rotation The participants reported that referral to an inpatient tapering programme specialised in prescription OUD, which offered a medically supervised tapering process along with alternative pain treatment options, such as opioid rotation, was a powerful motivator to initiate tapering. The availability of opioid rotation alleviated participants' concerns of inadequate pain relief and the severity of withdrawal. This was especially true for those who had previously undergone unsuccessful tapering attempts.

I was offered the inpatient tapering process (...) My husband and I were so happy there was something as we were desperate! (...) My husband also felt relieved [laughs] that I didn't have to do that at home, because he knew by then how it would go. (P15, female, 50s)

Barriers for completing an opioid tapering programme Recurring pain and withdrawal symptoms

Withdrawal symptoms and recurring pain during tapering hindered completion of a tapering attempt and reinforced reliance on opioids for pain relief.

I noticed within the 4 months that I quit with oxycodone that the pain became too extreme... We (GP and patient) decided to start opioid treatment again and within no time I was back on my old (high) dosage. I then said to the GP if there is no replacement for oxycodone, then I will not ever stop again. (P8, male, 40s)

Psychological problems and stress

Participants struggled to taper opioids during difficult times, including health problems, relationship issues, financial stress, social isolation and loss of loved ones. They often cited 'not the right timing' and relying on opioids to numb emotions like stress, depression and anxiety as reasons for previous failed attempts.

You think: 'I should really quit'. So, I gradually decreased my dosage as I was using 90–100 mg per day. It went well for a week or two. But then, the smallest thing happening could cause me to take an extra pill. Like when I had trouble sleeping, as I had not slept for almost two nights, I thought to myself: 'Just take one more and then you'll at least be able to sleep'. (P22, male, 60s)

Treatment factors: Tapering location, stigmatisation and tapering pace

Attempting to taper at home often disrupted daily activities and responsibilities, leading to patients breaking off their attempt.

My first attempt was bad. I am convinced this was due to my home situation, my child. I am in pain but the little one needs me, so I'll just use so I can move forward. (P16, female, 30s)

Participants reported feeling uncomfortable in addiction care facilities when grouped with illicit substance users without a specific prescription opioid tapering programme. Many stated that they did not view themselves as 'hard-drug addicts' or 'junkies'. Therefore, these intakes were often experienced as stigmatising and resulted in many not completing their tapering attempts.

In these clinics, they often focussed on the drug addiction side. They emphasised on illegal purchases, but I got it legally from the GP. So, I was like what am I doing here? (P1, female, 40s)

Additionally, participants reported a lack of shared decision-making regarding the pace of tapering. Some participants preferred to take small steps, while others preferred a more rapid tapering schedule. This unaddressed issue led to ineffective pain management and decreased willingness to continue with the tapering process.

Facilitators to complete an opioid tapering programme Intrapersonal and psychosocial factors

Readiness and intrinsic motivation to taper were considered driving forces to complete a tapering programme. Many participants also emphasised that receiving social support during tapering was essential for them to succeed.

My wife has guided me through this difficult period. You need that. I think that everyone has people around them that support you and genuinely mean we will support you also in this situation. (P10, male, 50s)

Additionally, the decision to enrol in an in-patient opioid tapering programme motivated patients to fully commit to the programme.

My main focus was on fighting this battle and I felt like I had to seize this opportunity with both hands. I knew that there weren't many options for me to turn to in the Netherlands, so I was very happy to hear that I could go there. (P10, male, 50s)

Medical tapering programme: opioid rotation

Participants described that the opioid rotation (methadone, buprenorphine/naloxone, buprenorphine) limited withdrawal symptoms, increasing the likelihood to complete the OUD treatment programme. Moreover, a number of participants reported that opioid rotation resulted in a reduction of side effects, improved pain management and a heightened sense of well-being.

I was able to taper due to another medication and I did not experience any suffering. I barely noticed anything during withdrawal, one time sweating and maybe some shaking, but no restlessness or vomiting. (P25, female, 40s)

Medical tapering programme: shared decision-making

Most participants emphasised the importance of shared decision-making during tapering, for example, regarding tapering pace or replacement drug dosing. This increased their sense of involvement and readiness for tapering.

I chose to stop in one go. (So in consultation with the GP) I was admitted to the hospital. One day later I quit taking oxycodone and received naloxone. I only had one very bad day, but that wasn't too bad as I had prepared myself for the worst! (P18, female, 60s)

Medical tapering programme: counselling/therapy

In addition to the opioid rotation, variations of pain therapy, counselling, cognitive behavioural therapy and/ or mindfulness training were offered prior to, during and after intake. Some participants felt that the extra therapy helped them finish their programme by improving their pain perception, pain management skills and decisionmaking about medication.

I learned a lot (in the offered pain therapy sessions after intake) that I could apply during my treatment and that saved me. (...) You're allowed to feel bad, that doesn't mean you have to use (medication) and I really had to learn that. (P25, female, 40s)

Medical tapering programme: supportive clinical environment

The ability to visit a specialised prescription opioid tapering facility was deemed decisive by some. The staff were praised for being knowledgeable regarding medication tapering, supportive, accessible and especially nonjudgmental. This allowed participants to fully dedicate their effort to and place trust in the tapering process.

The doctor kept his word which gave you trust. The nurses too, you were allowed to just be sick and they were able to support you, they really knew what they were doing! (P20, female, 50s)

Several participants also emphasised the importance of support from fellow patients who were tapering opioids and the option to join talking groups when struggling.

(The GP team) tried to let me taper oxycodone by myself but that never worked. At the academic hospital it worked, because I had fellow sufferers around me. (P14, male, 60s)

DISCUSSION

This study aimed to map CP patients' perspectives on prescription OUD tapering. It identifies barriers such as fear of ineffective pain management, lack of perceived support and facilitators such as medical assistance and social support. Recurring pain, setbacks, negative experiences and stigma are barriers to completing the OUD treatment. Willingness to taper, inpatient tapering and opioid rotation are facilitators.

Our findings indicate that many of our participants previously undertook unsuccessful tapering attempts at home, leading to withdrawal symptoms, recurring pain and psychological distress. These findings align with previous research on opioid tapering attempts in primary care.^{14 15 19 29} Insufficient guidance from primary care providers also contributed to failed tapering attempts at home. Therefore, it is crucial for a team of healthcare professionals, including physicians and pharmacists, to provide adequate guidance and support to patients during the entire tapering process. This team should also ensure that patients are aware of all available options for pain treatment, including opioid alternatives and referral to specialised tapering programmes. Increased training and education for both patients and providers can reduce failed tapering attempts and negative emotions towards the process. Ultimately, these efforts can improve patient outcomes and quality of life.

Consistent with the review study of Sud et al, we found that opioid tapering, particularly in challenging cases, benefits from a multidisciplinary care (MDC) approach.³⁰ Our study highlights the importance of shared decisionmaking throughout the treatment course, including tapering pace (gradual vs rapid), treatment location (outpatient vs inpatient) and dosing of rotation medication, in boosting patient engagement and completion rates.^{14 29 30} Therefore, healthcare professionals should increase their application of motivational interviewing, a person-centred approach that aims to address ambivalence towards behavioural change, and facilitate collaboration with patients towards successful opioid tapering. Motivational interviewing has shown efficacy in fostering therapeutic alliance, establishing personal goals and promoting treatment retention in patients with substance use disorder.^{31 32} Moreover, a recent pilot trial involving CP patients demonstrated the efficacy of motivational interviewing in reducing high-risk opioid use and alleviating pain severity through shared decision-making with primary care providers.³³

Our study adds to previous research that suggests offering (non-opioid) pain alternatives can facilitate tapering initiation.^{15 17–19} Our study provides new evidence that offering the rotation to long-acting (partial) opioid agonists, such as buprenorphine/naloxone or methadone, notably decreased patients' fears regarding ineffective pain management and withdrawal, and strongly motivated participants to initiate tapering. Furthermore, participants also described shorter withdrawal periods and effective pain reduction when using buprenorphine/naloxone or methadone, consistent with recent findings within this study population, allowing for a more positive tapering experience facilitating successful completion of the programme.^{34 35}

Specialised medical supervision, including staff understanding the complex nature of prescription OUD and CP and the tapering programme offering counselling and education options, allowed patients to experience a unique tailored experience, which positively impacted

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completion rates. Participants felt supported and understood, especially in contrast to previous tapering experiences. This aligns with existing evidence that the addition of psychological treatment (ie, pain education, CBT and graded activity) facilitates essential behavioural changes in patients, thereby enhancing the likelihood of pharmacological detoxification improving treatment completion.^{30 36 37} Also, we found that group and peer support, as well as family involvement, were considered additional effective behavioural components.³⁰

Additionally, CP patients with OUD often feel judged by healthcare professionals, especially as they were treated similarly to illicit substance users, focusing on the getting high aspects, which increased their feelings of shame and guilt. While this is not uncommon in patients with substance use disorders,^{28 33} it remains something that healthcare professionals should take into account during treatment. A non-judgmental attitude is necessary to ensure that patients feel safe and supported to discuss their struggles with opioid use and their goals for recovery.

To enhance care for prescription OUD patients, our findings indicate that an initiative should encompass key facets, such as expanding pain education, promoting shared decision-making during tapering discussions, providing support for behavioural change, implementing follow-up calls during and after tapering and increasing healthcare provider awareness for specialised care referrals. It is crucial to ensure that addiction clinics possess the necessary expertise before making such referrals. Given the diverse healthcare landscapes across countries, future efforts should focus on identifying optimal practices and areas for improvement in patient care to meet the growing demand for accessible and effective prescription OUD treatment.

Furthermore, addressing the increasing need for prescription OUD treatment in primary care settings, future work should focus on integrating specialised care elements tailored for primary care. Prior research highlights that healthcare professionals' familiarity and confidence in treating substance abuse positively affect their understanding of these patients.³⁸ Therefore, enhancing healthcare professionals' expertise in primary care is essential to improve the accessibility and effectiveness of prescription OUD treatment. This emphasises the need for collaborative efforts between policymakers and healthcare providers to ensure that primary care settings are equipped with the necessary resources and support systems for ongoing care.

Strengths and limitations

The qualitative study approach used in this study provided an in-depth and comprehensive understanding of patients' experiences and allowed for follow-up questions that revealed new and valuable insights that may not have been captured by quantitative research. The objective of this study is not to offer quantitative responses, such as determining the exact percentage of patients facing challenges with tapering or the frequency of associated risk factors; for these aspects, surveys and database research are required. Furthermore, the study achieved rigorous data saturation within a diverse sample, including individuals with multiple psychiatric comorbidities, who are often excluded from research.

It is important to acknowledge, however, that there may be limitations to the study findings. Recall bias may be present, as patients had to recall previous tapering experiences. The recruitment process may have excluded individuals who were not connected to the treatment sites, and our Dutch proficiency requirement may limit representation from individuals with diverse language or cultural backgrounds. Additionally, the study focused on participants who successfully rotated their opioids to buprenorphine or methadone. Therefore, the findings may not apply to individuals who are unwilling or unable to join such a programme.

Conclusion

To summarise, a patient should have a personal treatment goal, which should be combined with shared decision-making regarding opioid tapering to increase the successful treatment of prescription OUD. Healthcare professionals can use motivational interviewing to support these components. Additionally, referring patients to a specialised tapering programme with opioid rotation, a non-judgmental attitude and comprehensive psychological and behavioural change support can create a safe and supportive environment that fosters successful tapering and recovery.

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Competing interests None declared.

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Patient consent for publication Not applicable.

Ethics approval This study involves human participants, but the medical ethical review committee of Radboudumc declared that the study was not subjective to

the Dutch Medical Research Involving Human Subjects Act (WMO) (2020-7037). All procedures were approved by the Utrecht University Institutional Review Board (division of Pharmacoepidemiology & Clinical Pharmacology (UPF2018). Before the start of the interview, oral informed consent was obtained from all study participants. Identifying references to names, locations and institutes were anonymised in all transcripts. Participants gave informed consent to participate in the study before participation.

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Data availability statement Data are available upon reasonable request. Due to the confidentiality agreements and the sensitivity of the topic for research participants, supporting data are not publicly available. Data are however available upon reasonable request to the author (MLB). It should be noted that raw data are only available in Dutch.

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