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Caregivers' Attitudes Toward Treatment Length for Persons in Swedish Opioid Agonist Treatment. A Qualitative Interview Study

Christina Nehlin PhD ^{a,b}, Charlotte Wollert Brander BSc^b, and Caisa Öster PhD^{a,b}

^aDepartment of Medical Sciences, Psychiatry, Uppsala University, Uppsala, Sweden; ^bDivision of Psychiatry, Uppsala University Hospital, Uppsala, Sweden

ABSTRACT

Although opioid agonist treatment (OAT) has several beneficial effects, the issue of optimal treatment length remains unresolved. It is plausible that caregivers' attitudes toward treatment length are of importance to whether, how and when tapering off will take place. In this study, we investigated caregivers' attitudes toward treatment length by interviewing 15 caregivers from a variety of professions working in seven OAT treatment programs in Sweden. Data were analyzed using applied thematic analysis. The participants were generally hesitant concerning the idea of tapering off. Few of them had experiences of patients tapering off successfully. Many of them never brought up the subject unless the patient did so her-/himself. Only younger, socially stable patients were perceived to be suitable for tapering off. Participants also expressed a need among staff for education and ethical discussions on treatment length. A person-centered focus may be promoted by recurrently discussing treatment goals and by co-operating with patients to map the recovery capital of those interested in tapering. To further support caregivers in developing person-centered care, more knowledge of opioid use disorder and professional and interprofessional discussions of caregivers' own attitudes and beliefs are paramount.

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Introduction

Opioid use disorder (OUD) remains an important and persistent health and social problem worldwide (European Drug Report 2018; Degenhardt et al. 2014). Three high-income regions in the world have a particularly high prevalence: Australasia, Western Europe and North America. In Sweden, the estimated non-prescribed use of opioids is at a medium level compared with other European countries (Novak et al. 2016). Pharmacological treatment for OUD was first introduced in Sweden in 1966, an early follower of the pioneering work done by American physicians Dole and Nyswander (Dole and Nyswander 1965; Gronbladh and Gunne 1989). The idea of the treatment program was to use methadone to block craving and minimize withdrawal effects in persons with heroin addiction. The program creators Dole and Nyswander also emphasized the need for social support, such as help finding a job or housing support. Today, programs that deliver opioid agonist treatment (OAT) by Swedish legal definition should include social and psychological services, and are recommended to use methods such as cognitive behavioral therapy and motivational interviewing

(2020). Worldwide, opioid agonist treatment has consistently yielded beneficial effects, most importantly, reductions in mortality rates (Santo et al. 2021) but also reductions in criminality, accidents and infectious diseases (Mattick et al. 2009). Undoubtedly, OAT has saved many lives and helped a vast number of people transition to better life circumstances. Because of its proven efficacy, OAT has become more available and is now recommended as the primary choice of treatment for OUD in many countries, including Sweden (National Board of Health and Welfare 2019).

Research has also pointed out some areas for further development of OAT. One of them is the question of treatment length; whether and how to get off treatment in a planned and structured manner, and at what point in time (Blanco and Volkow 2019). Although long-term medication is beneficial, the issue of optimal treatment length is unresolved (Morgan et al. 2018). Retention rates vary substantially across programs, but it is estimated that only a smaller proportion of those entering OAT remain in the program for a meaningful length of time (Blanco and Volkow 2019; Williams et al. 2018). In previous studies, only 30–50% of those who started

CONTACT Christina Nehlin  christina.nehlin.gordh@neuro.uu.se  Department of Medical Sciences, Psychiatry, Uppsala University, Uppsala, Sweden

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treatment remained after six months (Morgan et al. 2018; Winstock, Lintzeris, and Lea 2011), which indicates a large share of disrupted treatment attempts. Unplanned discontinuation increases mortality risk substantially (Sordo et al. 2017).

Many who participate in OAT have a desire to end the treatment (De Maeyer et al. 2011; Winstock, Lintzeris, and Lea 2011). In one study, 62% of patients expressed a strong desire to come off treatment within the next six months and 15% were quite interested. Only 12% stated they were not at all interested in getting off treatment (Winstock, Lintzeris, and Lea 2011). Similar proportions have been found in other studies (Stein et al. 2019). From the individual's perspective, there may be several reasons for limiting or discontinuing OAT. The pharmaceuticals used in OAT are potent and may have health impacts. Side effects (e.g., on cognitive ability and sexual function) are commonly reported (Noble and Marie 2018). Patients also report feeling "stuck in limbo," an intermediate state between recovery and continued life with addiction (Gronnestad and Sagvaag 2016; Notley et al. 2013). Further, the strict forms for distribution of pharmaceuticals may infringe on personal integrity (Cioe et al. 2020; De Maeyer et al. 2011; Nehlin et al. 2022). In a recent study from our group on patients' reasons for wanting to leave OAT, participants stressed the need for treatment to be focused on the individual (Nehlin et al. 2022). They also called for staff to be supportive in making decisions about treatment goals.

It is plausible that caregivers' attitudes toward treatment length are of importance to whether, how and when tapering off will take place (Gutwinski et al. 2014; Rosenbaum and Murphy 1984). In the present study, we explored OAT caregivers' attitudes toward treatment length. We were interested in their thoughts about OAT as a lifelong treatment, and how they talked with their patients about treatment length.

Methods

Setting

Historically, in Sweden, provision of OAT has been under a polarized debate since the introduction in 1966. The numeral development of programs was very slow over the first 20 years and the programs have been subject to strict regulations. Initially, admittance to the Swedish methadone program was only allowed for persons who had been addicted to heroin for four years or more and who could verify that they had made at least three serious attempts to become drug free. Participants in the program

should be surveilled during intake daily the first six months of treatment. Any use of illegal drugs during treatment should lead to discharge (Gronbladh and Gunne 1989). Today, regulations have become less prescriptive and programs more accessible, regarding number of places available, eligibility criteria, and discharge regulations. An individual treatment plan must be established, including dosage, voluntary group or individual therapy, and social support if needed. Leaving OAT is recommended primarily as a response to the patient's wish to do so (National Board of Health and Welfare 2020). In Sweden, about 50% of OAT patients receive methadone and 50% buprenorphine (2020).

Procedure and participants

Managers at 10 OAT programs all over Sweden were contacted by e-mail with an invitation to participate in the study. They were asked to forward the invitation to their coworkers of all professions. In the invitation letter, caregivers interested in taking part in an interview, and who had a minimum of one year's experience, were encouraged to contact the researchers. The interview focus, treatment length of OAT, was presented. Caregivers who contacted the researchers were given further information and gave their verbal consent.

In all, 15 caregivers, working in seven different OAT programs all over Sweden, contacted the research team. They were all interviewed. Among them were five nurses, four physicians, four social workers, one psychologist and one treatment assistant. All except one of the interviewed caregivers had more than three years' experience working with OAT, some of them intermittently over a long period of time, making it difficult to specify in years. For a specification of each participant's profession, see Table 1.

Table 1. Participants' professions.

Number	Profession
1	Physician
2	Physician
3	Social worker
4	Social worker
5	Social worker
6	Social worker
7	Nurse
8	Psychologist
9	Nurse
10	Treatment assistant
11	Nurse
12	Nurse
13	Physician
14	Physician
15	Nurse

Data collection

Interviews were conducted by telephone ($n = 9$) or at a personal meeting ($n = 6$). Each interview was recorded on an Mp3 player and transcribed verbatim. The interview sessions ranged from 12 to 26 minutes, with a median length of 20 minutes. Participants were interviewed following a semi-structured interview guide developed by the research team. Participants were asked to describe their thoughts about the length of OAT and whether they considered it to be a lifelong treatment. They were also asked whether they typically bring up the question of tapering off and ending the treatment with their patients, and if so, to describe how they approach the topic.

Interviews were conducted by authors CN and CWB, both trained in interviewing techniques. CN is a researcher and a former social worker with experience in psychiatric care as well as in qualitative research. CWB is an experienced social worker at an OAT service. All authors have extensive experience in psychiatric care, substance use disorder (SUD) health care, or both. The project was approved by the Swedish Ethical Review Authority, decision no. -2020-00541.

Data analysis

The interview data were analyzed using applied thematic analysis (Guest, MacQueen, and Namey 2012), which derives from a broad range of theoretical and methodological perspectives. The primary concern of applied thematic analysis is with presenting participants' thoughts and experiences as accurately and comprehensively as possible. Themes were identified and analyzed inductively; they were formed based on data only and not on predetermined hypotheses. After 12 interviews had been performed, the research group discussed if saturation was achieved, since we found that the last three interviews provided little new information. To ensure saturation, we performed three more. Once 15 interviews had been conducted, we could determine that information from the last few did not produce any changes in the themes. Thus, we deemed that saturation had been achieved (Guest, Bunce, and Johnson 2006; Malterud, Siersma, and Guassora 2016).

The transcripts were read independently and several times by all authors. Meaning units – words and sentences of interest in relation to the study aims – were coded. After joint discussions with all authors, the codes were sorted into preliminary themes. The

material was re-read, the themes were reviewed and the subthemes 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 consensus was achieved and themes were judged to concisely describe the content.

Results

In the analysis, three themes were identified: (1) *Experiences and expectations form attitudes toward treatment length*, (2) *Patients suitable or not suitable for tapering off* and (3) *Discussing tapering off with patients*. The themes and subthemes are presented below, with verbatim quotes to illustrate the findings.

Theme: experiences and expectations form attitudes toward treatment length

Participants' attitudes toward treatment length were described as having been formed by previous experiences, education and what they felt colleagues expected. Some participants described their experiences of working with tapering. Such experiences were rare and descriptions were sometimes accompanied with a sigh, because so few patients had succeeded. A recurrent belief was that many patients feared being discharged if the tapering failed. Examples were provided of programs aimed at ending OAT using controlled tapering, but those programs were not particularly successful and are not in use today.

"I haven't tapered off that many patients over the years, maybe 10, and five of them are back in treatment. So, to be honest, for those on heroin, I don't believe in tapering off, really. But I don't tell the patients that". (#14)

All participants were well aware of the particularly severe dependence associated with opioids. There were participants who used biological terms to explain why patients need to stay in OAT over a long period of time.

"You have to be humble and realize that there's been a strong imbalance reaction with cortisone and that the hippocampus and amygdala are involved, and it's the amygdala that's overactive and the hippocampus that's shrunk." (#7)

The subject of treatment length was not discussed among staff members; only one participant reported discussing it with colleagues. Rather, participants felt there was an implicit expectation that they would automatically understand the clinic's attitude toward tapering.

“When I was new, I came here and thought that it was obvious that you taper after a while, but then I understood that it’s more of a rule that you see it [OAT] as lifelong.” (#8)

The participants did not know their colleagues’ actual opinions about treatment length, but could sometimes guess there were very different attitudes concerning how to work with patients. Participants highlighted the need for more education to discuss treatment length at a higher level, as well as a need for discussions about moralizing attitudes among staff.

“Some [staff] have been here only here for a couple of months and have cocksure opinions. There isn’t so much talk about treatment length. New staff, they only talk about disciplining the patients in terms of setting limits and pulling themselves together”. (#10)

Theme: patients suitable or not suitable for tapering off

Most participants reported having clear opinions about what made a patient suitable for discussions of tapering off, and what made a patient not suitable. Age was considered an important factor; younger persons were deemed to be more appropriate for tapering off than persons with long experience of addiction and of OAT.

It’s the ones who have a bit more ahead of them, and less addiction behind them. There’s more to work with; maybe they’re not so much into living completely outside the norm and society, which you may be if you’ve lived all your life in the world of addiction. (# 6)

Participants generally believed that patients are more likely to succeed at tapering off if they function well socially, which means they need to have a job and stable housing. Other prerequisites mentioned were being motivated and resourceful. The two participants who mentioned a time perspective had very different opinions, one stating that tapering is possible after a stable period of 1–2 years, the other mentioning a period of 10–15 years.

The participants were quite unanimous in describing what makes an OAT patient not suitable for discussions of tapering off. Those patients were typically described as older, with long experience of both addiction and OAT, and with a complicated social situation that could include mental disorders. Their type of medication could also be a complicating factor; some participants reported that patients receiving methadone have particular problems with tapering off.

Patients who are trying OAT for the first time, and maybe come in on buprenorphine, they may be able to be

on OAT for a delimited period. But the ones who’ve tried several times and who receive methadone, there I almost see it as a lifelong treatment. (#15)

One participant described child soldiers with opioid dependence as an example of persons who have acquired irreversible brain damage.

“Child soldiers from Syria, Iraq, Iran, who have used opiates from the age of 10. OK, the brain has its plasticity and may adapt to different situations. But these guys, they need lifelong treatment. Their brains can’t work without opiates, or opioids.” (#2)

One aspect frequently emphasized was the high prevalence of comorbidity and thus the importance of ensuring patients receive other kinds of therapy and support in addition to OAT.

“There isn’t any patient who abuses who’s 100% psychiatrically healthy. It’s sometimes the reason why you’re stuck.” (#1)

Some participants stressed that staff attitudes toward treatment length were subordinate to the patient’s own desire to delimit treatment. They reported that, at treatment onset, it was common for young persons to express a desire to undergo OAT for only a limited period. Women who had prospects of getting pregnant were specifically said to have such intentions. The participants simply accepted that this was what the patient wanted, and they had no other opinion.

One participant stated that it was sometimes others – family, friends and social workers – who influenced the patient’s wish to come off treatment more than the caregivers did.

“They [the patients] are greatly affected by what the people around them think. There are tons of opinions about OAT, mostly not based on science at all, but only opinions and moralizing.” (#13)

Theme: discussing tapering off with patients

About half of participants reported not having actively raised the issue of tapering off with their patients. For patients who were non-compliant with treatment due to, e.g., drug use, any discussion of tapering off was considered out of the question.

“Now we’re fighting for this person to be drug-free next week. . . And the longer it works, the more long-term goals you can have. It’s difficult to say right from the start that the goal is to taper off treatment.” (#12)

Still, participants reported believing it was necessary for clinicians to identify and recurrently discuss individual treatment goals with the patient, even if they did not live up to that standard themselves.

“Discuss more, now we’re not discussing [treatment length] at all with the patients. We don’t say anything, which implicitly means for life.” (#15)

On the other hand, tapering off could be discussed on the patient’s initiative. Such discussions usually took place in connection with the annual revision of the treatment plan, which included consideration of long-term goals.

“Only if the patient her-/himself brings it up, like ‘I want to try to end treatment,’ or ‘I want to try to taper to see how I feel, maybe I can make it.’ We only talk about it when they start having those thoughts themselves.” (#9)

Although the participants did not always bring up the subject of tapering off in discussions with patients, they thought their own opinions as caregivers were important.

“We have to believe that it [tapering off] works. If we have doubts, then we’ll never make the patient believe it works.” (#3)

Participants who reported actively bringing up the subject of tapering off said they often chose to do so at annual controls and with well-functioning, compliant patients. The arguments they presented to patients included reduced side effects and increased access to emotional life. Reduced dosage could be an alternative if the patient was reluctant to ending treatment.

“You have to search for the lowest, efficient dose. With reduced doses comes a lot of benefits. You’ll become more awake, alert – you’ll gain a lot from it.” (#2)

Some participants reported talking with their patients about length of treatment at an early stage: at the assessment interview or early on in treatment. Others found it more appropriate to bring up the subject regularly during the later phases of treatment.

“I believe they think it’s good that I bring it up. Thought provoking. Not that I’m trying to push them. But just ‘Have you thought about for how long?’” (#10)

“I plant a seed and then I keep coming back to it. – ‘What do you think, is this a lifelong treatment, do you want it for life?’” (#3)

One participant pointed out that OAT is expensive and requires considerable resources, meaning it is important to encourage patients to end their treatment.

“A lot of resources, money and premises and doctors and psychologists, expensive medicines are used. And then you have to somehow get some effect back. Not just that the patient comes here year after year, without any success.” (#1)

Discussion

By investigating caregivers’ perspectives, the present study sheds light on what has been described as an

important but unresolved area in need of additional knowledge: Safe discontinuation of medication for OUD (Blanco and Volkow 2019). The participating caregivers generally expressed hesitant attitudes toward the possibility of a successful tapering-off process for their patients. Few of them had experiences of patients tapering off successfully. Many of them never brought up the subject of tapering off, unless the patient did so her-/himself, while others meant they needed to discuss personal treatment goals with patients in more depth and at various stages of treatment. They were well acquainted with the explanatory model depicting OUD as a chronic, relapsing disease, and the model impacted their attitudes toward tapering off to varying degrees. Participants also talked about the need, among staff, for education and ethical discussions on treatment length.

The present results showed that attitudes toward tapering off were far from unanimous, ranging from participants who regularly brought the subject up with their patients, to those who felt OUD had had a critical and irreversible impact on patients’ ability to lead a life without pharmaceuticals. Similarly differing attitudes were found in a recent study of OAT and stigma (Dickson-Gomez et al. 2022). In that study, some interviewed caregivers saw treatment as a temporary tool to help people achieve abstinence; they advocated tapering after a specified period of time. Other caregivers were reluctant to taper off, claiming that OUD is a chronic disease and that patients should remain in OAT on a long-term basis, particularly considering the increased risk of overdose. According to the authors, these differing attitudes derive from the notion that only abstinent patients are truly recovered. Other researchers have pointed to the discouraging odds of completing a tapering-off process and remaining abstinent. Zweben et al (Zweben et al. 2021). concluded that tapering off should not be recommended at all and that caregivers should rather put their effort into helping patients stay in OAT. There is presently no consensus as to the definition of recovery from substance use disorder, but researchers have advocated the idea that recovery is a process rather than an outcome and, thus, more than symptom reduction (Ashford et al. 2019). Above all, the recovery process is, or should be, individual, with self-defined treatment goals. Abstinence may be the preferred outcome for some, and for others it may be impossible, for many reasons.

Bearing in mind the large share of patients who are interested in coming off OAT, there seems to be a gap between their wishes and what the caregivers interviewed in the present study believe is possible. It was a common conception that tapering off is

mainly possible for a distinct group of OAT patients: younger, healthier individuals with a good social network. On the other hand, the participants rarely discussed treatment length with their patients. It is likely that regular discussions on treatment goals would put more focus on the individual patient's hopes and desires for the future, providing a clearer view of what is actually possible.

In previous research, person-centered care, in which patients are part of the decision-making, has been advocated in substance use treatment and in OAT (Marchand and Oviedo-Joekes 2017; Strike and Guta 2017). A more explicit person-centered focus could lead to safer tapering off and better outcomes that are more in line with patients' individual treatment goals. However, there are indications that clinics serving patients undergoing OAT are less likely to use person-centered care than are clinics providing more general health care (Marshall, Maina, and Sherstobitoff 2021). Although OAT is in many ways a restrictive treatment model, there are possibilities to shift to a more person-centered model.

The participants noted that, today, younger persons seek OAT more than they did previously, which puts pressure on caregivers to include discussions of treatment length. This was also seen in a Canadian study with young people in OAT, in which the most commonly reported goal of patients was to taper off or stop medication (Chai et al. 2021). The authors concluded that there is a need to explore the reasons why young persons want to taper off or stop treatment and called for guidance on safe discontinuation.

The present study was performed with OAT caregivers from seven services all over Sweden. The variation in setting and profession provides a broad picture of the attitudes that persons undergoing OAT might encounter. The authors' pre-understanding of clinical work with patients contributed to their understanding of the studied subject. It is also possible that the authors interpreted statements from caregivers in a manner in line with their own experiences rather than reflecting what the participants actually intended. To pay attention to this risk, the issue was continually discussed within the research group. Through these internal critical discussions, the risk of bias was minimized.

The interviewed caregivers were generally reluctant about tapering off OAT and did not commonly bring up the issue of ending treatment with their patients. A person-centered focus may be promoted by recurrently discussing treatment goals and by co-operating

with the patient to map the recovery capital of those interested in tapering off. To further help caregivers in developing person-centered care, more knowledge of OUD and professional and interprofessional discussions of caregivers' own attitudes and beliefs are paramount.

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ORCID

Christina Nehlin PhD  <http://orcid.org/0000-0002-9404-5183>

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