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'Crisis' and 'Everyday' Initiators: A Qualitative Study of Coercion and Agency in the Context of Methadone Maintenance Treatment Initiation

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Abstract

Introduction and Aims—Patient attrition is common among people enrolled in methadone maintenance treatment (MMT) programs and most pronounced during the first year of treatment. However, the experiences of patients initiating MMT have been overlooked in the literature. This study explores experiences of MMT initiation among MMT patients, focusing on contextual influences on MMT initiation and perceptions of MMT and their subsequent influence on treatment retention.

Design and Methods—Semi-structured qualitative interviews were conducted with 39 MMT patients in Vancouver, Canada. Individuals reporting enrolment in MMT were recruited from within two ongoing cohort studies comprised of people who use drugs. Interview transcripts were analysed using an inductive and iterative approach.

Results—Two groups of MMT initiators were identified: (i) 'crisis initiators' prescribed methadone following critical transition events, such as incarceration or pregnancy; and (ii) 'everyday initiators' enrolled in MMT as part of routine healthcare utilisation. While most 'crisis initiators' and some 'everyday initiators' described experiencing coercion during MMT initiation, 'crisis initiators' were further subjected to the coercive leveraging of their vulnerability to motivate 'consent' for MMT. 'Crisis initiators' developed negative views towards MMT and were more likely to discontinue treatment. Long-standing patient– provider relationships and open dialogue were associated with more positive views regarding MMT, regardless of the circumstances of initiation.

Discussion and Conclusion—Findings underscore the need for clear and effective communication regarding treatment regimens and expectations during MMT initiation. Furthermore, training in trauma-informed care may help reduce perceptions of coercion and rates of early treatment termination.

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Keywords

methadone maintenance treatment; qualitative research; treatment retention; low threshold methadone; trauma informed care

Introduction

Methadone maintenance treatment (MMT) is a frontline treatment for opiate dependence that has been shown to decrease opiate use and related harms [1], including HIV and hepatitis C infection [2-4], and criminal activity [5, 6], while improving social functioning and HIV treatment outcomes [7-10]. Early MMT models recommended that people initiating treatment receive a range of psychosocial supports, including an initial 6– 8 week in-patient stabilisation period involving social and psychological supports [11] and outpatient care with integrated psycho-social supports [12]. MMT models have gradually moved away from psychosocial interventions outlined in earlier treatment models [13, 14], in part because of evidence that higher-threshold approaches deter treatment enrolment and retention [15]. While this has improved access to MMT, it has also given rise to new initiation experiences, with many patients being enrolled in MMT by unfamiliar physicians and without access to ancillary psychosocial supports.

The initiation phase of MMT is characterised by significant changes in people's everyday routines [16]. New MMT patients must sometimes simultaneously manage withdrawal symptoms while titrating up to effective doses and managing side effects [16, 17]. Meanwhile, patients must adjust their daily patterns and income generation activities to accommodate daily pharmacy visits, as well as doctor visits for drug screening and prescription refills [18, 19]. Epidemiological studies have shown that patient attrition is common among those enrolled in opioid substitution therapies [20, 21], and highest during the first months of treatment [20, 22]. In British Columbia (BC), Canada, 64% of patients in opioid substitution therapies ended treatment within 12 months in 2013 [23], up from 60% in 2006 [21].

While previous research on patient retention has focused on methadone dosage levels [24], significantly less research has explored the role of patient experiences of MMT initiation on treatment engagement. Negative perceptions about MMT prior to initiation have been shown to predict early treatment termination [25], and patients seeking opioid agonist treatment were found to have elevated rates of major depressive disorders and post-traumatic stress [26]. Despite evidence pointing to a range of issues leading to early attrition, there has been a general absence of research focusing on the MMT initiation period, and there is limited understanding regarding how perceptions of MMT form during the early stages of treatment and evolve over time. Indeed, some epidemiological studies of MMT have actively excluded patients dropping out of treatment 'early' [22], potentially obscuring analysis of factors affecting retention. Furthermore, while previous qualitative studies have elucidated how experience of treatment regulations and client–staff interactions in the context of ongoing MMT regimens shape treatment outcomes [18, 27-30], little is known about how initiation experiences shape perspectives on MMT and contribute to treatment retention. This

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literature has generally focused on patient experiences of MMT in aggregate, rather than considering how these experiences vary across different stages of treatment (including initiation). Consequently, the extant research does not fully reflect the experiences of patients during the critical phase of MMT initiation, and overlooks the roles of prescribing physicians in shaping MMT experiences.

The need to understand factors associated with early treatment attrition is of particular relevance in BC, Canada, where early attrition rates have increased despite demographic trends associated with increased retention and programmatic changes [14, 23]. BC's provincial MMT program has rapidly expanded over the past two decades, increasing from 2827 clients in 1996 [14] to 15 418 clients in 2013 [23]. Currently, opioid substitution therapies in BC are predominately made up of patients taking MMT but includes 1482 patients enrolled on suboxone [23]. The College of Physicians and Surgeons of British Columbia is responsible for administering MMT in the province. In order to prescribe methadone, physicians must complete a training program developed by the College of Physicians and Surgeons of British Columbia. Methadone is typically dispensed and consumed at community pharmacies under direct supervision. In BC, individuals receiving income assistance receive MMT free of charge. Higher income earners pay some or all of the cost of their MMT dispensation, which averaged \$3219 per patient in 2013/14 but may be subsidised by private insurance coverage [23]. Although take home doses of methadone may be authorised, these concessions require evidence of social stability and patient stabilisation (e.g. 12 consecutive weeks of negative urine drug tests) [31]. While psychosocial services and supports are considered integral to the provincial MMT program [23], a programmatic review found that these supports are provided inconsistently [32].

Because of the lack of studies on early experiences with methadone, we undertook this study to explore experiences of MMT initiation to better understand the ways in which perceptions of MMT are shaped during this stage of treatment, and their subsequent impact on treatment retention. We were particularly concerned with examining the formation of negative and positive perceptions of MMT following treatment initiation, and the role of patient/provider interactions and external influences (e.g. poverty, significant life events) in shaping these perceptions.

Study Design and Methods

We draw upon semi-structured qualitative interviews conducted with MMT patients as part of an ongoing ethno-epidemiological study of experiences with drug treatment programs in BC's Lower Mainland region. Participants were recruited from two ongoing cohort studies that include more than 2000 people who use drugs, the Vancouver Injection Drug Users Study (HIV-negative cohort) and AIDS Care Cohort to Evaluate Exposure to Survival Services (HIV-positive cohort), which have been described in detail elsewhere [33, 34]. In brief, cohort participants are recruited from a storefront research office and through community outreach, and complete structured questionnaires and clinical assessments at baseline and every six months thereafter.

Between February and July 2014, cohort participants were recruited into the larger study if they reported enrolment in any kind of drug treatment in the last 6 months. Thirty-nine of the 45 participants recruited during this period reported lifetime exposure to MMT (see demographics in Table 1). Study personnel explained the larger study to eligible participants and scheduled interviews with those wishing to participate. Three trained interviewers conducted the interviews at the cohort study research office. Interviewers explained the study procedures and obtained written informed consent prior to the interviews. Participants were remunerated with a \$30 honorarium following the completion of their interview. In addition to lines of inquiry focusing on experiences with specific drug treatment programs, all 39 of these participants were asked to describe their first experience with MMT initiation in detail, and then asked to describe subsequent MMT experiences. Interviews averaged 45 min in length, were audio recorded and transcribed verbatim.

Thirty-nine participants narrated their experiences initiating MMT with an emphasis on how initiation contexts influence views and engagement over time. Interview transcripts were imported into NVivo, a qualitative software program, to facilitate coding. Data were coded using both deductive and inductive analytic methods [35]. We used a preliminary coding framework comprised of a priori codes informed by the interview guide and regularly revised the coding framework to accommodate new codes that emerged during the analysis. We then re-coded the data following the establishment of the final thematic categories to ensure their reliability [35]. Our coding strategy also sought to elucidate gendered and racialised experiences of MMT initiation. However, while we did not find that these experiences were demonstrably affected by the participant's race, specific gendered patterns (e.g. MMT initiation during pregnancy) were noted.

Results

'Crisis' and everyday methadone initiation

Participant accounts underscored how MMT initiation experiences functioned as a critical site where participants' perceptions of MMT were formed, often with lasting effects on treatment engagement. A key distinction emerged between: (i) 'crisis initiators' who were prescribed methadone during critical transition events, such as imprisonment, difficult or unplanned pregnancies, or a major health event; and (ii) 'every day initiators' prescribed during routine healthcare utilisation (e.g. a visit to a family doctor or a walk-in clinic). Most participants (n = 23/39; 59%) were 'crisis initiators' and held more negative beliefs about methadone than 'everyday initiators' (n = 16/39; 41%). Crisis initiators expressed feelings of regret in relation to MMT initiation, a lack of ownership over treatment and a rhetorical focus on negative side effects of methadone. These effects were not demonstrably affected by participant's race or gender.

Interestingly, the effect of a crisis initiation persisted regardless of the number of past initiation experiences. All participants described their initial MMT initiation experience, and many described experiences re-initiating MMT subsequent to interruptions in treatment. MMT initiation during a critical transition event had a persistent negative effect on treatment compliance and perceptions of MMT that endured, in many cases, for years. While this extended timeframe might have impacted the accuracy of self-reported experiences, and

wherever possible was taken into account in our analysis, it proved important in generating insights into the longitudinal impact of different types of initiation experiences. Distinct from explicit negative perceptions about MMT, both every day and crisis initiators described experiences of coercion with regard to MMT initiation. The following sections explore experiences of coercion and agency in the context of MMT initiation, focusing on patient–provider interactions (e.g. trauma awareness, disclosure) and their relationship to subsequent perceptions and experiences of MMT.

'Hitting rock bottom' and lack of trauma awareness in 'crisis' MMT initiation

'Crisis initiators' emphasised how MMT initiation coincided with critical transitional events in which they 'hit rock bottom', such as hospitalisations, difficult or unplanned pregnancies, HIV-positive diagnoses and incarceration. We use the term critical transitional event to encompass the diverse and emotionally intense experiences of participants ranging from the stressful (e.g. unplanned pregnancies) to the potentially traumatic (e.g. HIV-positive diagnoses). In many cases, participants described how physicians who lacked 'respect' for the stress and trauma associated with these events leveraged their vulnerability to obtain consent for MMT initiation. In these low agency initiations, participants articulated how this lack of awareness among physicians about their experiences of vulnerability and traumatic stress led to the prioritisation of MMT initiation over their more immediate emotional, physical, and social care needs. The following interview excerpt illustrates how the interplay between a lack of dialogue and consideration of patient needs shaped one participant's MMT initiation experiences and led her to distrust MMT and regret treatment initiation:

When I woke up from the coma, one of the first things that happened was the [physician] came to see me... Her telling me, "You're a candidate for methadone". I can't specifically remember what they said, but I think, if somebody had actually pulled me aside and explained that my body had already gone through withdrawal and in fact I was already successfully clean, if I had understood that, I would've said, "No". I would've been ecstatic. But because of my blurriness, I just said, "Yes, I need it". Just because I was a user, my automatic response was, "Yes, I need it". In fact, I didn't need it. Had that been explained properly to me, I would have saved myself years of heartache that I ended up going through. [43-year-old Aboriginal woman].

This excerpt also reveals the ways in which patient agency can be reduced when prescribed methadone in a state of duress, given power differentials between physicians and patients [16, 36]. This participant's first experience with MMT was profoundly shaped by these patient/provider interactions. Later, this participant described how this experience precipitated a 'major relapse' and contributed to feelings of aversion towards MMT that would last for three years, illustrating how perceived coercion at methadone initiation can have long-term consequences for patient perceptions of MMT. As noted in previous studies of MMT, the stigma associated with illicit drug use shapes treatment guidelines and leads to forms of social control and surveillance that impute the untrustworthiness of the subject [37, 38]. Similarly, the prescription of MMT in crisis situations was perceived by participants as the product of the stigma associated with illicit drug use. Among participants, this was seen

as a way to extend the social control aspects of MMT [19] into the lives of recalcitrant MMT patients.

MMT as a 'bridge' and coercion in patient-provider interactions

Both groups of initiators emphasised that a lack of communication regarding the long-term commitment and potential side effects of MMT at the time of initiation eroded trust and constrained their agency in treatment decisions. Participants described how physicians presented MMT to them as a 'bridge'—a necessary but temporary solution to assist them in progressing towards eventual drug abstinence. The metaphor of the 'bridge' precluded discussion regarding potential harms stemming from MMT (e.g. withdrawal associated with treatment interruptions) and demands of MMT regimens (e.g. daily directly observed treatment, monthly physician visits). Furthermore, participants expressed that, because physicians framed the 'goal' of MMT as drug abstinence, there were limited opportunities to discuss harm reduction uses of MMT. This presentation of MMT had the effect of reducing participants' feelings of agency in the decision to initiate MMT. As a result, many participants who initiated MMT as a 'bridge' felt that they had been misled by prescribing physicians, and instead enrolled in a long-term treatment program requiring strict adherence to minimise the potential for suffering (e.g. methadone withdrawal). For example:

With the HIV, I was trying to straighten things out... I agreed [but] I didn't want to go on methadone. I disagree with everything about it. I think people should go clean. I think they should be tapered... Putting me on methadone for five years was the stupidest thing they ever did. Now they're telling me that I probably can't get off methadone because I've been on it for five years. I'll probably need 10 ml for the rest of my life. Fuck that! [38-year-old white woman].

This participant's frustration is illustrative of how a lack of full disclosure of treatment requirements was viewed by many as a way to coerce them into enrolling in an MMT program. While MMT programs that are long-term and high dose are an evidence-based best practice [24], participants felt that these program expectations were not communicated. Many initiated MMT with the expectation that it would be temporary step towards abstinence, only to later learn that program expectations differed from their goals. Many participants read the conflict that arises from the tension between their goals (e.g. short-term MMT as a step towards abstinence) and program expectations (e.g. long-term treatment) as a lack of consideration of their goals in relation to their drug use.

Some crisis initiators also reported that they were subjected to transactional forms of coercion (i.e. 'do this or else') that were more extreme than the lack of disclosure of program expectations. For example, several participants reported that physicians in hospitals coerced them into initiating MMT by threatening to limit their access to pain medication. This form of coercion leveraged the fear of severe suffering stemming from pain and withdrawal symptoms to coerce 'consent' to MMT initiation. These experiences demonstrate the coercive ways in which physicians can deploy bio-medical authority (e.g. denying prescriptions) to compel MMT initiation. For example:

I had a heart infection – endocarditis. I went into the hospital. They were giving me morphine for a while. [The doctor] for addicts came in and he prescribes the

morphine and stuff like that. He kept me on morphine because of my heroin. I was wired to heroin, and then he asked me if I wanted to go on methadone. I heard methadone was crap, right, and I told him, "No". Then he said, "Okay, but you're here for three weeks and in one week your morphine's up. I really think you should go on it." [...] I think it was one week before I was so sick [that] I was like, "Okay, I'll try it." [55-year-old white man].

Coercion, conspiracy theories, treatment engagement

Participant accounts illustrated how perceived coercion during MMT initiation corresponded to lower levels of trust and negative views towards MMT, which sometimes led to MMT discontinuation. It was common for participants who experienced coercion at initiation to ascribe negative and conspiratorial motives to their prescribing physician, with one participant explaining, 'it was all about money, money, money'. This perception stemmed from media accounts of fees associated with monthly physician appointments for methadone prescription refills, and perceived relationships between physicians and 'predatory pharmacies' in the Vancouver area [39]. Participants who felt coerced during MMT initiation were more likely to report extreme side effects (e.g. having their teeth 'crumble') and question the medical efficacy of MMT. For example:

Who invented it was Hitler. Some of his lab guys invented it for stamina. You know, his guys in the army, to give them stamina. I thought, "Well, it doesn't really give you stamina". If you take enough of it, you get all lethargic. However, what he was doing was giving them a little bit, which at first does give you that feeling and then you really get wired...depending on the amount. [...] I thought at the beginning [that] it's bad for your teeth. It robs you of your calcium, gets right into your bones. [52-year-old white woman].

The conspiratorial views that circulated among participants regarding the broader motivations of MMT—for example, the view reported elsewhere that methadone was 'invented' by Hitler to control Nazi soldiers [16]—and the extreme side effects that they reported provided a rhetorical tool to frame their discussions of coercion at the time of initiation.

Critical transitional events and patient agency in initiation

Not all participants who initiated after [hitting rock bottom] reported feeling coerced by their prescribing physician. Among these participants, critical transitional events fostered dialogue with their physicians characterised by feelings of choice, open exchange of information about the risks and potential harms of MMT and time between the initial consultation and treatment initiation. For example, one participant reported initiating methadone after becoming pregnant because of the potential for child apprehension if she was not enrolled in treatment. However, she felt supported and informed about this initiation because MMT initiation aligned with her goals (i.e. maintaining child custody) and she received assistance from a local non-profit organisation:

I had lots of help. [A women's health organisation] was helping me. I got information of which doctor and where to go get my methadone from. So, I got

hooked up to see this doctor... I stayed, on methadone for...Well, when I first got on it, I was on it for about three years. I got a job. I smartened up. [31-year-old Aboriginal woman,].

Where participants described feeling empowered, MMT initiation became a powerful moment precipitating a major life change. For example, one participant described actions she took when a doctor refused her request to enrol in MMT immediately after learning she was pregnant:

I said, "OK, well, write me a prescription saying I need heroin every day, 'cause I know my mom will give me the money if it's from a doctor kind of thing". He's like, "I can't do that. That's not legal". I said, "I'm not leaving this office 'til you give me methadone". Like, "Fuck you". Right? "I'm pregnant, and I'm not going back out to sell my ass". So, I got on methadone that day. He buckled. [40-year-old White woman]

This participant expressed a powerful feeling of ownership over MMT and actively advocated for treatment on her terms. In similar cases, participants experiencing a critical transition event leveraged MMT to their own ends, re-affirming their own agency in the process. High agency initiations often involved a more established patient/provider relationship and multiple consultations prior to prescription. Supportive physicians who had established relationships with patients, experience with addiction medicine and cultural competency facilitated positive experiences.

While higher agency initiation experiences were more common among everyday initiators, with 35% of everyday initiators describing little or no coercion in their initiation, some crisis initiators (20%) also reported having higher levels of agency. In these cases, time for deliberation and accurate and adequate information were key. One participant described initiating MMT after repeatedly being rearrested for violating a condition of her parole that required abstinence:

They're like, "Well, why don't you try methadone?". I'm like, "Well, I never thought of it. I'll read up on it". I was in jail at the time they started me on methadone, hoping that I would be stable before...when they let me out.... They didn't just give me a prescription in hand and say, "Go to the drug store, as opposed to the dealer". I was stable. I got out and I never thought of heroin. I've completed my sentence in the community because of methadone. [50-year-old white woman].

Discussion

Our findings illustrate how MMT initiation functions as a critical site of narrative formation, where participants' views about MMT are shaped by the circumstances surrounding their initiation and their interactions with prescribing physicians. 'Crisis initiators' were more likely to perceive MMT initiation as coercive, to have negative or conspiratorial views of MMT, to report poorer treatment engagement and early treatment attrition. Both 'crisis' and 'everyday' initiators described how full disclosure of the risks and benefits associated with MMT can mitigate feelings of coercion, underscoring the importance of patient/provider dialogue.

While previous qualitative studies have largely concentrated on patient experiences of MMT regimens in methadone clinics [16, 29, 30], our study benefits from an analytic focus on MMT initiation and its effects on treatment perceptions. Importantly, we found that many patients engage in discussions regarding MMT with physicians following traumatic or stressful experiences associated with critical illness or major life changes. While many patients already held negative views about methadone, we found that, among crisis initiators, such views were more likely to stem from real or perceived coercion and subsequent loss of agency during MMT initiation. Most notably, crisis initiators emphasised how physicians leveraged patients' vulnerability following critical transition events to obtain consent for MMT. While previous studies and treatment guidelines have identified such events as avenues for initiating MMT [40, 41], our findings suggest that this approach can have negative impacts on treatment retention.

To this end, our findings point to the need to consider approaches that are responsive to psychosocial needs and the immediate conditions that prospective MMT patients are contending with. The broader vulnerability of prospective MMT patients shapes initiation experiences and can be counterbalanced by programmatic changes committed to fostering feelings of choice, empowerment, and trust through dialogue, and sensitivity towards circumstances surrounding decisions to seek treatment. One example of a programmatic response to these concerns comes from the large and growing literature on the importance of trauma-informed practice in addiction medicine [42]. This literature established the importance of principles of trust, choice and a strengths-based approach in service delivery to vulnerable populations [42], and specifically emphasised a sequential approach to treating traumatised patients [43]. This approach would discourage MMT initiation during critical transition events when other more immediate psychosocial needs (e.g. housing, physical and mental health) are not also being addressed. Training physicians, administrators, dispensing pharmacists and others responsible for prescribing methadone to vulnerable populations on principles of trauma-informed practice could foster an ethic of care that improves treatment retention and reduces feelings of coercion [44-47].

Notably, in working to empower patients and reduce feelings of coercion, trauma-informed approaches are consistent with the principles of 'low threshold' MMT models [28, 30]. Recent studies have highlighted the potential of 'low threshold' MMT models to empower patients and promote treatment retention by accommodating harm reduction and instrumental uses of methadone [28, 30]. We found that some individuals exercised agency by initiating MMT following critical transitional events when instrumental uses of treatment were aligned with their personal goals (e.g. maintaining child custody). Making counselling and other psycho-social supports available alongside MMT programs may help patients navigate their initiation, although such services should be voluntary and separate to ensure that they do not raise the threshold of MMT.

Finally, MMT initiation is a tumultuous time, and overall treatment efficacy is improved by implementing policies and practices that are sensitive to overt and tacit forms of coercion that patients may experience during MMT initiation. While a pregnancy, incarceration or major health event may seem like an opportunity to encourage MMT initiation, such an approach may do more harm than good. For patients, the widespread feelings of coercion

around MMT prescription fostered conspiracy theories that gave expression to very common experiences of MMT prescription as an unwelcome effort to control their lives. As noted by ethnographers in other contexts, conspiracy theories often function as a way for marginalised communities to contest official discourses and scientific authority [48]. In this regard, conspiracy theories shed light on the ways in which coercive practices render MMT suspect and challenge views of MMT as a 'silver bullet' cure for the complexities of opioid dependency.

This study has several limitations. Our study asked patients to recollect experiences that happened, in some cases, many years in the past. While this allowed us to take a longer view of the effects of different initiation experiences, there are potential limitations to this data that should be considered (e.g. accuracy of self-report). Future studies focused on initiation could focus on immediate after effects and draw on a purposive sample of more recently initiated patients. In addition, our study was cross sectional and did not fully account for changes to BC's methadone program over time and recent improvements in training for Addiction Medicine in Vancouver. Our study was undertaken in a specific setting where methadone is provided by primary care physicians and dispensed through community pharmacies (Vancouver, BC), and might not be transferable to other settings and programs operated differently. Furthermore, because some participants had initiated MMT more than five years ago, there were limitations to their recall of events and variability in program guidelines.

In conclusion, our study illustrates how MMT initiation functions as a critical site of narrative formation where coercion and power imbalances foster negative views about MMT, which adversely impact treatment retention. Many people began their MMT treatment recovering from major life events, and often developed negative, even conspiratorial views about MMT. Greater emphasis on trauma-informed care during MMT initiation has the potential to increase responsiveness to patient needs, and thereby improve treatment retention.

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Table 1

Participant characteristics

Participant characteristics	n = 39
Age	
Mean	46 years
Range	26 – 64 years
Gender	
Men	22
Women	17
Race	
White	28
Aboriginal ancestry	10
African–Canadian	1
Health status	
HIV-positive	20
Drug use (30 days prior to in	nterview)*
Heroin	26
Crack cocaine	19
Cocaine (injected)	13
Crystal methamphetamine	9

* Possible to report the use of more than one drug