RESEARCH BRIEF

“Just Maintaining the Status Quo”?

The Experiences of Long-term Participants in Methadone Maintenance Treatment

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This Research Briefing documents key findings from a qualitative study of long-term clients of methadone maintenance treatment (MMT) in Dun Laoghaire Rathdown. The research aimed to examine client perspectives on MMT, with particular attention directed to the lived experience of methadone treatment, participants' lives and relationships and their health and social care needs.

Summary of Findings

- The primary perceived benefit of MMT centred on *stability* and *normality,* with participants reporting that methadone treatment had improved their ability to fulfil their roles as family members, parents and friends.
- While a large number of participants reported that MMT had conferred benefits, they simultaneously expressed hugely negative sentiments about methadone and the treatment system within which methadone is embedded.
- The clinical experience of MMT was perceived by a large number as instrumental rather than caring and as founded on the assumption that, as patients, they were not trustworthy, capable or responsible.
- Among this study's participants, levels of social integration can be described as extremely low. The vast majority were unemployed, a considerable number were currently homeless or precariously housed and, for many, family and broader social ties were tenuous.
- The dominant experience of being a methadone user was one of stigmatisation. Stigma negatively shaped participants' lives, both socially and emotionally, and the impact and consequences of stigma were numerous and severe.
- Participants in the study reported a host of physical health problems, including both chronic and acute illnesses and a range of everyday health problems.
- Mental health problems were widely reported, with depression and anxiety being the most commonly cited mental health conditions.
- Reported levels of contact with support services apart from MMT were generally low. For women, in particular, service engagement posed the threat because it could potentially expose their ongoing participation in MMT to community members, family and friends
- MMT was not generally perceived as supporting 'recovery' because 'treatment' was not perceived to address their broader social and health care needs.

The Research Context

The research was conducted against a backdrop of clear evidence throughout Europe, including in Ireland, of an ageing drug treatment population. Internationally, there is growing recognition of the health and social needs of individuals who are long-term participants in drug treatment but research is only beginning to examine the complexities of being an 'older' person who has been accessing treatment for a prolonged period. This is the first study in the Irish context to specifically address the experiences of individuals who are long-term clients of methadone maintenance treatment.

Methodology

The research was qualitative and used the in-depth interview to examine participants' experiences of MMT. To be eligible for participation in the study, service users had to be over the age of 18, have accessed drug treatment for the first time at least 10 years prior to participating in the research and report at least one episode of opioid substitution treatment since they first entered treatment. Participants were recruited through contact with specialist addiction clinics, community and voluntary addiction services, primary care settings and a supported temporary accommodation service, all based in the Dun Laoghaire Rathdown area. The research and, consequently, the recruitment process, was particularly focused on enlisting clients of specialist addiction services, individuals who would generally be expected to have less stability in their lives than those attending primary care settings.

The Study's Participants

- Of the 25 individuals who participated in the research, 16 were male and 9 female.
- The average age of participants was 43 years and first entry to a MMT programme occurred, on average, at 23.8 years.
- All of the study's participants had first accessed MMT more than ten years prior to interview, with 16 reporting that they first entered into treatment more than 20 years previously.

Other Information

This research was funded by the Dun Laoghaire Rathdown Drug and Alcohol Task Force, supported by Southside Partnership and the Dun Laoghaire Rathdown Community Addiction Team

A full copy of the report, "Just Maintaining the Status Quo"? The Experiences of Long-term Participants in Methadone Maintenance Treatment, can be downloaded from:

https://www.dlrdrugtaskforce.ie/

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Main Findings

Positive Experiences: Methadone, Stability and Normality

- A majority of participants reported that methadone treatment had impacted their lives positively in at least one respect. The most commonly stated benefit was that methadone had brought *stability* and *normality*, meaning that MMT had improved participants' ability to fulfil their roles as family members, parents and friends.

> *"Yeah, it's (methadone) kind of settled me. I found that I was better at the house and better looking after the kids … rather than being chaotic, you know. I was making dinner, everything was just normal, you know. What I classed as just normal to me … not wanting to use all the time and just trying to have a normal family life with the kids" (Yvonne, age 40-44).*

- MMT was reported to have provided a release from the stress of having to procure drugs on a daily basis by a number of male participants, leading to a reduction in criminal activity and criminal justice contact.

Ambivalence about MMT

Ambivalence was a core, cross-cutting theme to emerge from participants' accounts of MMT. Thus, while treatment benefits were reported, a complex constellation of negative experiences were recounted.

- MMT was perceived to be binding rather than emancipating, particularly with the passing of time. Participants routinely used terms such as "lifer", "hostage" or "liquid handcuffs" to convey the routine of MMT, which was frequently likened to a 'holding space'.

> *" …But like the phy (methadone), it's only stalling the problem, it's not fixing it. It's just keeping it at a certain stage … I just feel like the phy is holding everyone. And like, one or two will cross over and get jobs or whatever but the majority of people are being kept in the same place for years" (Dillon, age 35-39).*

The 'Culture' of the Clinic

- A majority identified a host of negatives associated with the clinical experience of MMT. These critiques were fixed firmly on the 'culture' of the clinic, with three key themes – *lack of care*, *dehumanising experiences* and *diminished autonomy* – permeating participants' accounts.
- Perceptions of a lack of care were strongly related to the treatment experience, which was depicted as concentrated primarily or solely on the substitute drug or 'script': *"It's just literally like, 'Here for your methadone, there's your script, go over there, do your urine, 'bye'"* (Rachel, age 40-44).
- Participants described limited communication or meaningful interaction with their prescribing physicians. The requirement to provide urine samples under supervision was almost always said to be humiliating and depicted as reinforcing the stereotypical image of drug user as "junkie".

> *"It (providing urine samples) was mortifying … It sort of seems pointless as well. It's like they're just going through the motions, them and me, you know. But now it's just to maintain and they sort of*

> *reinforce that junkie mentality, that you need something every day, whether you need it or not" (Lorraine, age 40-44).*

- In general, participants did not feel that they had any 'say' or control over their treatment regime. Several did not feel able to discuss a dose reduction or detoxification plan, aspirations which they felt were strongly discouraged by their prescribing physicians.

> *"Not once have I heard a doctor encourage me to come off methadone. Even when I was wanting to come off I was actually told that I couldn't" (Dillon, age 35-39).*

- Rather than describing their interactions with their prescribing physicians as helpful, supportive or empathetic, participants felt discredited, humiliated and punished.

> *"Judging you on your performance, as in like, 'Did you do drugs this week and, if you did, you're getting punished over it' … I mean why, what's the point in punishing the person for it and making them worse. I mean I didn't see the point in that" (Chris, age 35-39).*

Social Reintegration

The research examined participants' lives beyond MMT in order to understand the extent to which they had achieved 'social reintegration', a policy aim concerned with the individual's position in wider society.

- Only three participants (all women) were employed at the time of interview. Participants experienced significant barriers to labour market participation, including their lack of educational qualifications and the demands associated with the daily routine of MMT. Concerns about the views of employers and the consequences – should they become aware of their drug use history or participation in MMT – were also articluated.

> *"You feel you can't get a job. Like what if your job starts at 9 o'clock and you haven't got your Phy in you all day … And then you're thinking like, 'What if they ask for a medical?' Even though they don't know me … like who wants to employ someone who is on methadone?" (Bernie, age 40-44).*

- The housing situations of study participants can be characterised as a mix of stability and instability. Some reported housing security and had been living in local authority or private rented housing for a significant period of time. However, a considerable number of others were vulnerably housed and at risk of homelessness while seven were currently accessing homelessness services.

- While some participants reported improved family contact, a large number described their family relationships as fragile, strained or even fraught. Participants' social circles tended to be extremely limited and most had few, if any, dependable or trusted people in their lives.

> *"I mean, trust-wise I'm not one for trusting people much myself, I've got a few issues around that … Friends-wise I would have one person I would consider a real friend. The rest are sort of people you met through drugs and stuff so I wouldn't consider them close friends" (Alvin, age 40-44).*

- Many participants reported self-isolating practices, often describing daily lives characterised by seclusion and loneliness.

Stigma

Accounts of stigmatising experiences were pervasive. Stigma operated on multiple levels in the lives of participants:

- At the institutional level, many described feeling stereotyped by the treatment settings they attended and disrespected by clinic and pharmacy staff.
- Stigma was also experienced by participants in their communities, leading many to attempt to conceal their methadone use and clinic attendance from family members and friends.
- Other experiences of stigma related specifically to being an older drug user in treatment and the fear of being judged because of their continued engagement in MMT.
- Growing older as a long-term methadone patient exacerbated feelings of stigma and elated stress.

> *"That one word straightaway gives them your whole history: methadone. It lets them know that there is a threat and then, if you're in your 40s, and then they're thinking, 'Oh god, she's in her 40s and she's still taking methadone, she probably still takes heroin', you know what I mean. Because that word methadone, it's not associated with any other illness" (Catherine, age 40-44).*

- Stigma diminished quality of life by instilling and perpetuating feeling of 'otherness' and shame, negatively affecting self-esteem, and mental health. Stigma also contributed to social isolation with participants frequently reporting that they felt excluded from community and family life.

Physical Health

Participants reported a wide range of physical health problems.

- Sixteen of the 25 participants were living with a chronic illness apart from hepatitis C. Four had been diagnosed with cirrhosis of the liver and three with a thyroid disease. Others (n=9) reported chronic illnesses included respiratory, renal and coronary diseases. More than half reported that they suffered from insomnia and these participants also frequently described low energy levels, fatigue and irritability.

Mental Health

A complex range of mental health problems were reported, with only one participant stating that they were not currently experiencing mental health issues.

- The most commonly reported mental health problem was depression – reported by 19 respondents – and eight of these participants also reported anxiety. Two had attempted suicide in the past while one reported suicidal ideation. Accounts of poor mental health were in fact woven through the narratives, with participants frequently making reference to lifelong mental health problems that sometimes spanned from childhood.

> *"I've been like this for, like I've been diagnosed with depression since my teens. Now I've had sort of good spells between then … when I got away from (former partner) I had a good spell when I was working … but, yeah, it's pretty much always like that. It's sort of worse lately" (Lorraine, age 40-44)*

- For a majority, mental health problems where ongoing, irrespective of participants' individual circumstances. Many were susceptible to self-isolation as a coping strategy while a large number were

- self-medicating by using street-sourced benzodiazepines to manage stress, anxiety and stigma, as well as crises associated with experiences of bereavement and loss.

Health and Social Care Service Utilisation and Engagement

- Almost half of participants reported no contact with support services beyond MMT. Seven of the nine female participants were not attending any additional support services. Those who were utilising other services, including self-help groups, counselling, parenting support and community or voluntary sector services, found them to be a valuable source of support.

"Like people who are out there in the clinics come in here (community and voluntary sector addiction service) and talk to these key workers any time, like. It's very, it's good to have someone there that's willing to talk to you and listen and not just judge you, you know" (Dillon, age 35-39).

- The accounts of participants who were not accessing support services and suggest that non-engagement had many complex dimensions. For women in particular, managing the perceptions and expectations of others – including neighbours, family members and friends – acted as a barrier to service engagement. Some described their participation in MMT as shrouded in secrecy and concealment.

"But yeah, there is a dirty stigma to being on methadone. I don't care what everyone says, 'Oh they're not using, they're not a drug addict'. But there is still a stigma out there, you know"

[And nobody at work knows?) *"No, Jesus, no"*

[Is there anyone in your life who knows about the methadone?) *"No. Not one person knows that. No"*

The Meaning of 'Recovery'

For a considerable number, "getting clean", most often equated with getting off methadone, featured strongly in how participants articulated their understanding of recovery.

"(Recovery) is off the methadone and off everything. Clean, like proper clean" (Yvonne, age 40-44).

However, recovery was more often depicted as a process of self-improvement and a journey towards a new and better life.

"I don't want to be on it (methadone). It's the worst … I'm hoping, I want to have my kids around me, like back in my life, to be able to go and visit them and talk to them on the phone and have them come visit me. Have a place where they can actually come visit me" (Richie, age 40-44).

The experience of MMT was often perceived as thwarting participants' recovery goals, not simply because of the 'bind' of methadone but also because 'treatment' was perceived as focused primarily on the administration of a substitute drug and not on their broader health and social care needs.

[When you hear the word recovery? What does that mean to you?]

"It used to be something sort of, you know, it used to be a goal I had or something that I sort of, 'One day I will'. But now it just doesn't mean anything … it doesn't even get used within the drug treatment services. It doesn't get used because recovery isn't their aim, it's just maintaining the status quo" (Lorraine, age 40-44).