

“JUST MAINTAINING THE STATUS QUO”?

**The Experiences of Long-term Participants
in Methadone Maintenance Treatment**

Paula Mayock, Shane Butler, Daniel Hoey

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THE EXPERIENCES OF LONG-TERM PARTICIPANTS IN
METHADONE MAINTENANCE TREATMENT

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Foreword

This report, *“Just Maintaining the Status Quo”?* will make an important contribution to developing a response to older and long-term drug users, in line with Action 2.1.23 of *Reducing Harm, Supporting Recovery: A health-led response to drug and alcohol use in Ireland, 2017-25*. I am particularly pleased that the research team succeed in giving voice to those interviewed, thereby ensuring their perspectives can now enter the public and policy domain, and to have impact.

We know from national and international reports that Methadone Maintenance Treatment (MMT) succeeds with both public health and individual aims. Indeed, the research reported in this study confirms that MMT has delivered important benefits to the individuals interviewed. We need however, to be deeply concerned with the levels of negativity expressed about MMT, the treatment system in which it is embedded, and that participants continue to be marginalised within their communities and society.

This report poses an important challenge for the treatment system, for the Task Force and for the various community projects and services here in the Dun Laoghaire Rathdown community. We need to stretch our abilities, our imagination and our resources to bring direct focus to the needs of this group, to support their social re-integration.

Finally, I would like to express my appreciation to all those involved in this report, particularly the research team led by Dr. Paula Mayock (TCD), the research participants who were interviewed, the Task Force liaison group led jointly by Geraldine Fitzpatrick (Community Addiction Team) and Dr. Barry Cullen (Task Force coordinator), Fardus Sultan (Farend-Net) who designed the report for print, and Southside Partnership DLR for its ongoing commitment to and support for both this project and the work of the Task Force more generally.

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Executive Summary

This publication documents the findings to emerge from a qualitative study that examined the experiences of long-term clients of methadone maintenance treatment (MMT) in the Dun Laoghaire Rathdown area of South Dublin.

The research was conducted against a backdrop of clear evidence throughout Europe, including in Ireland, of an ageing drug treatment population. Internationally, recognition of the health and social needs of individuals who are long-term participants in drug treatment is growing but research is only beginning to examine the complexities of being an older person who has been using drugs and/or 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 MMT.

The Study: Aims and Research Methods

The research aimed to examine client perspectives on MMT, with particular attention directed to the lived experience of methadone treatment, participants' social relationships and their health and social care needs. 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 in-depth interview was used to explore a broad range of issues deemed relevant to understanding participants' experiences of MMT. These included: drug use and drug treatment history; experiences of drug treatment; education and employment; housing; family and peer relationships; physical and mental health; perceived social and health care needs and participants' perspectives on the future. To aid the construction of a detailed sample profile, a brief questionnaire was administered to record demographic and health-related data.

Sample Profile

Gender and Age

Twenty-five individuals participated in the research and, of these, 16 were male and 9 female. The average age of participants was 43; eight were between 35 and 39 years, 14 were aged 40 to 49 years and the remaining three were aged 50+ years.

Education and Employment Status

Participants generally had low educational attainment, with six having no formal educational qualifications. More than half (n=13) had progressed to Junior Certificate level before leaving secondary education for various reasons; one had progressed to Leaving Certificate level and a small number of others (n=3) had attained a third-level certificate.

At the time of interview, just three (all female) were employed full-time and all other participants relied on social welfare payments.

Drug Use History, Entry to MMT and Duration of Treatment

Drug use was almost always described as commencing during early adolescence in the company of peers in locations in, or in close proximity to, their home neighbourhoods.

The average age of participants' initial drug use was 14.2 years and the average age of initiation to heroin use was 19.1 years. 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.

Housing and Homelessness

At the time of interview, nine participants (six of them female) lived in either local authority housing or housing provided by an approved housing body. Two (both female) lived in private rented sector accommodation while five (all male) lived in the home of a family member.

One participant was moving between the homes of his partner and a family relative (a situation of hidden homelessness) while one lived in a privately owned home. Finally, seven participants, six of them male, were living in transitional homeless accommodation. Over half (n=14) of the study's participants, the majority of them male (n=10), had experienced homelessness at some point in their lives.

Overall, this profile includes several markers of social exclusion for the sample as a whole in the form of experiences of homelessness and insecure accommodation, inadequate education, poor employment skills and low income.

The Experience of Methadone Maintenance Treatment

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, thus improving 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 and more settled ... 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 provided a release from the stress of having to procure drugs on a daily basis, leading to a reduction in criminal activity and criminal justice contact. Several participants also reported health benefits, often stating that methadone had "probably saved my life" (Kevin, age 55+).

Exploring Ambivalence

Ambivalence was a core, cross-cutting theme that permeated participants' accounts of MMT; while treatment benefits were reported, a complex constellation of negative experiences were recounted.

These narratives draw attention to a perception that methadone was binding rather than emancipating and, particularly over time, participants questioned the extent to which the chemical and psychological 'bind' of MMT mirrored their addiction to heroin. Respondents 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

While participants' accounts focused on the impact of methadone, as substance and 'substitution', on their everyday lives, a majority also identified a host of issues 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 instrumental and 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 with their prescribing physicians and this lack of interaction was perceived as demeaning. The requirement to provide urine samples under supervision was almost always said to be humiliating and also depicted as reinforcing the stereotypical image of drug user as "junkie".

"It 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 or in their treatment futures. 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)

Trust, which had to be earned – and could be abruptly withdrawn in the event of providing 'dirty' urines – was deeply embedded in these accounts.

"... the doctor will let it be known that s/he just doesn't trust you ... If your urine was dirty s/he'd say, 'Either go to the (larger) clinic or I'm cutting you down to such and such.'" (Rachel, age 40-44)

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'. Fuck off, like. People have slip-ups, do you know what I mean, they relapse. 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 and the Management of Stigma

The study 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.

Employment

Participants experienced significant barriers to labour market participation. Low educational attainment and the demands associated with the daily routine of MMT were frequently mentioned issues but participants were in fact more likely to express concerns about the views of employers – and the consequences – should they become aware of their drug use history or participation in MMT.

"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, there is stigma straight away, like who wants to employ someone who is on methadone?" (Bernie, age 40-44)

Housing and Homelessness

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.

There are some noteworthy gender differences in the housing situations of study participants, with women more likely to live in local authority or approved body housing and men more likely to live in the home of a family member or to be currently accessing homeless accommodation.

Social Ties and Relationships

While some participants reported improved family contact, a large number described their family relationships as fragile, strained or even fraught. Several expressed feelings of shame over the family ruptures associated with their drug use, sometimes simultaneously articulating a mix of hurt and anger about how they were perceived by family members, despite their efforts to make changes in their lives.

Relatively few participants reported that they had 'good' friends with whom they interacted or socialised on a regular basis. 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)

Prominent in the accounts was the extent to which participants engaged in self-isolating practices, with a large number describing daily lives characterised by seclusion and loneliness.

"I'm not really doing anything active or I'm not getting out, I'm not changing, I'm not finding new things to do. I'm still kind of isolated away, like I'm not finding hobbies or anything, you know ... Yeah, I just don't do anything." (Dillon, age 35-39)

Managing Stigma: "I'm always hiding and ducking and diving"

Accounts of stigmatising experiences were pervasive, with participants frequently confronting stigma on multiple levels as part of everyday life. Growing older as a long-term methadone patient exacerbated feelings of stigma and stigma-related 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)

A powerful, yet frequently unspoken and silenced experience, addiction and drug treatment stigma undermined participants' ability to participate and experience a sense of belonging in their communities.

Furthermore, the range of institutions with which they interacted – including those related to drug treatment, housing and health – frequently served to legitimate discourses that reinforce and uphold the stigma of drug use, addiction and methadone treatment.

Methadone, Health and the Meaning of 'Recovery'

Physical Health

Participants in the study reported a host of physical health problems, including both chronic and acute illnesses and a range of everyday 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 reported chronic illnesses included respiratory, renal and coronary diseases (n=9). Thirteen respondents reported that they suffered from insomnia, typically describing sleep disturbance or difficulty initiating or maintaining sleep.

These participants frequently described low energy levels, fatigue and irritability. Several also reported poor appetite and found meeting their nutritional needs challenging.

Mental Health

A complex range of mental health problems were reported by the study's participants, with only one stating that they were not currently experiencing mental health issues.

The most commonly reported mental health problem was depression – described by 19 respondents – and eight of these participants also experienced 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 of a large number 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 – most often related to depression and anxiety – were ongoing, irrespective of participants' individual circumstances or the specific details of their biographical pasts. 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 (n=12) 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 services and support suggest that non-engagement had many complex dimensions. For women in particular, managing the perceptions and expectations of others – including individuals in their community, family members and friends – acted as a barrier to service engagement.

For these participants, service engagement represented a threat because it could potentially expose the reality of their lives to others in the community. Indeed, some described their participation in MMT as shrouded in secrecy and concealment¹.

"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. Some framed recovery as getting back or regaining something that they had prior to their drug dependence – a home, positive family relationships and/or contact with family members.

"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)

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

1) We have not attached a pseudonym or age range to this excerpt in the interest of protecting the anonymity of this study participant.

*[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)*

Conclusions

Explaining Ambivalence

- ◆ While a large number of participants conceded that MMT had conferred benefits and perhaps even saved lives, they simultaneously expressed hugely negative sentiments about methadone and the treatment system within which methadone is embedded.
- ◆ In many ways, the criticisms of the service users interviewed mirror those emanating from research that has examined the perspectives of stakeholder groups: rather than being seen as a valid and enabling treatment, methadone was viewed as a form of social control by the state that maintains the status quo – trapping service users into life-long addiction and impeding their prospects of full and meaningful participation in society.
- ◆ Much of the ambivalence attached to MMT can be explained by their interactions with treatment services and clinics, their prescribing physicians and other professionals associated with the regime of methadone maintenance. While acknowledging the kindness and empathy of some professionals with whom they interacted in surgeries, clinics and pharmacies, participants did not generally view their experiences in positive terms. The treatment experience 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.
- ◆ A prominent feature of the treatment experience was a perception that, as clients or patients, they had no say in their treatment. By and large, participants felt controlled rather than in control with little evidence of them feeling able or entitled to share their experiences or to articulate any aspirations or needs related to their treatment.

Recovery and Social Reintegration

- ◆ One of the spatial metaphors commonly used in recovery policy documents is that of 'pathways': ideally, clients still using illicit drugs or prescribed opioid substitutes should be moved along a pathway to abstinence and full social reintegration. However, many in this study who had previously anticipated an end to their addiction careers and to its management by healthcare services now saw themselves as trapped or indefinitely consigned to a regime that made it difficult, if not impossible, to discuss reducing dosages of methadone or becoming drug free.

- ◆ Among this study's long-term MMT clients, levels of social reintegration can be described as extremely low: the vast majority were unemployed and did not see any realistic prospect of future labour market participation, a considerable number were currently homeless or precariously housed and, while some reported improved family relationships, for others family ties were tenuous and relatively few had family members who were in a position to provide regular or ongoing financial, social or emotional support.
- ◆ Put differently, their 'recovery capital' was low, meaning that most did not have access to the kinds of economic, social or personal resources considered necessary to bolster and sustain the recovery process.

Ageing, Methadone Maintenance Treatment and Health

- ◆ This study's participants reported chronic health problems, including hepatitis C, liver cirrhosis and a range of respiratory, renal and coronary diseases. Fifteen (60%) had tested positive for hepatitis C, although a large number of these participants had received, or were currently receiving, treatment for the condition. Acute health problems, often related to infections linked to (past) injecting drug use were also widely reported, as were everyday persistent problems related to pain, insomnia, fatigue, low energy levels and irritability.
- ◆ Mental health problems were widely reported, with depression being the most commonly cited mental health condition. For a large number, depression was accompanied by anxiety, with both conditions often attributed by participants to their drug use histories and related traumatic life events or experiences. The prevailing picture to emerge was of individuals who struggled to cope with everyday life and in particular with social interaction, leading many to self-isolate as a coping strategy.

Stigma and its Consequences

- ◆ Among the individuals interviewed, the dominant experience of being a methadone user was one of stigmatisation and, for a majority, stigma operated on multiple levels.
- ◆ At the institutional level, participants described numerous ways in which they felt stereotyped by the treatment settings they attended and disrespected by clinic and pharmacy staff. Stigma was also experienced by participants in quite distinct ways within the communities where they resided, impacting their experiences and interactions and 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 and rejected because of their continued engagement in MMT.
- ◆ Stigma negatively shaped participants' lives, both socially and emotionally, and the impact and consequences of stigma were numerous and severe. Stigma diminished quality of life by way of instilling and perpetuating feeling of 'otherness' and shame, negatively affecting self-esteem, self-efficacy and mental health. Stigma also contributed to social isolation with participants frequently discussing ways in which they felt excluded from community and family life.

Managing Addiction within the Healthcare System

- ◆ The emergence of a specialist addiction service in Ireland, as elsewhere, may be seen as an indication of a continuing reluctance by the more established branches of medicine to accept such responsibility.
- ◆ At present, management responsibility for addiction treatment in Ireland is based within the Social Inclusion stream of the Health Service Executive – which perhaps is a realistic location given the considerable overlap between drug addiction and social deprivation but is a far cry from the aspirations of those who contend that addiction is a disease. Wherever they are located, however, it is hard to see how any health service initiatives can succeed if it fails to secure cooperation and resourcing from a wide range of external agencies and sectors – dealing with housing, income maintenance, education and training.



CHAPTER 1

Long-term Participation in Methadone Maintenance Treatment: An Introduction to the Study

Methadone maintenance treatment (MMT) is a licit medication-assisted treatment for individuals with an opiate dependence. The primary function of MMT is the substitution of illicit opiates with a synthetic opioid that alleviates the cravings and withdrawal symptoms associated with opiate addiction (Mullen et al., 2012). Most commonly administered orally as a liquid syrup (Hunt et al., 2003), methadone is the most widely available opiate substitute for the treatment of opiate-dependent persons in Ireland. A key aim of MMT is to reduce the harms associated with opiate dependence and to provide a level of stability for individuals whose drug use has led to chaotic and harmful behaviour.

Internationally and in Ireland, MMT has demonstrated success in several areas of stabilisation, including reductions in illicit drug use (Cox et al., 2007; Comiskey et al., 2009; Fareed et al., 2009; Teesson et al., 2006), high risk drug-related behaviours (Corsi et al., 2009; Cox et al., 2007; Gowing et al., 2008) and criminal activity (Buker et al., 2011; Comiskey et al., 2009; Cox et al., 2007; Lind et al., 2005; Sheerin et al., 2004). Retention in MMT is associated with a substantial reduction in the risk of overdose mortality in people dependent on opioids (Sordo et al., 2017).

This chapter provides an introduction to the current research, which is qualitative and examines the experiences of long-term participants in MMT in one geographical area in Dublin that has an established history of concentrated drug problems. The chapter starts by presenting trends in treated opiate use, demonstrating clear evidence of an ageing drug treatment population in Ireland and throughout Europe. Next, the literature on drug treatment and ageing is reviewed, highlighting a range of challenges that older individuals who are long-term participants in MMT may potentially confront. An overview of the research context is provided and the chapter concludes by outlining the organisation and content of the report.

Treated Opiate Use in Ireland and Europe: Key Figures and Trends

The most recently published data for Ireland from the National Drug Treatment Reporting System indicates that in 2016 there were 9,227 cases of treated problem drug use, with

opiates (mainly heroin) remaining the main problem drug reported over the period 2010-2016. However, as a proportion of total cases reported, there has been a drop in treated opiate use year-on-year from 58.1% in 2010 to 47.0% in 2016 (Health Research Board (HRB), 2018). Trends throughout Europe are similar; the European Monitoring Centre for Drugs and Drug Addiction (EMCDDA) reported that between 2006 and 2015 the number of new opiate users entering treatment in the European Union (EU) decreased by 45% compared to a decrease of 9% for all drugs (EMCDDA, 2017).

Evidence of an Ageing Drug Treatment Population

Europe is experiencing a pronounced ageing of its population and by 2050 around one quarter of the population will be aged 65 and over (European Commission, 2014). Published statistics also show that Europe's drug-using population is ageing and that meeting the needs of older drug users is a pressing issue for treatment services. This is particularly the case in many western European countries, including Ireland, which saw Europe's first heroin epidemics during the 1980s and 1990s. The total number, as well as the proportion of older, problematic drug users has increased significantly throughout Europe over the past decades and this group now makes up an increasing number of drug treatment clients in many countries (EMCDDA, 2010). Ireland experienced its first heroin epidemic in the 1980s when the wider availability of heroin in Europe found its way to areas of Dublin characterised by social and economic deprivation (Butler, 1991). In the mid-1990s, a second opiate epidemic developed in Dublin with the identification of a new generation of young heroin users (O'Gorman, 1998). Many individuals who began using heroin during these early epidemics subsequently underwent MMT and many continue to experience prolonged periods of continuous or interrupted MMT (EMCDDA, 2010).

While the numbers of new opiate users in treatment are in decline throughout the EU, the number of older opiate users, particularly those in MMT, has increased significantly over the past decades. The mean age of individuals entering MMT increased from 33 to 38 years between 2006 and 2015 while the proportion of MMT clients over the age of 40 years increased from 20% to 40% during that same period (EMCDDA, 2017). In addition, the average age of drug-related deaths (which are mainly opioid-related) increased by 5 years between 2006 and 2015 and, among these deaths, the proportion aged above 40 years increased from around one in three in 2006 to nearly one in two in 2015 (EMCDDA, 2017). Research on adults in opiate treatment populations in the US also shows a striking increase in the proportion of older patients in treatment (Han et al., 2015).

Mirroring these trends, the proportion of people who are older and availing of treatment for opiate use in Ireland has also increased. In 2015, 42.5% of treated opiate users nationwide were over the age of 35 years compared to 27% in 2009. In the Dublin region, this trend in age development of the treated opiate using population is more pronounced: while 31.5% of individuals treated for opiate use in 2009 were over the age of 35, this proportion increased to 54% by 2015 (HRB National Drugs Library, 2017). A recent study, which used four data sources to estimate the number of opiate users in Ireland in 2014 (Hay et al., 2017), also indicates clear shifts in the age structure of the opiate-using population. In total, there were an estimated 18,988 opiate users in Ireland in 2014, which corresponds to a prevalence rate

of 6.18 per thousand people aged 15 to 64 years. A majority were male (69%) while more than half (60%) were found to be in the 35-64 age group, compared to less than one-third in 2006, suggesting a definite ageing cohort effect.

Methadone Maintenance Treatment: Long-term Participation, Ageing and Health

The classification of 'older' people within drug treatment research is frequently defined by long histories, often extending for 20 years or more, of problematic drug use, typically commencing in the teenage years, meaning that an older user could be an individual in their 30s (EMCDDA, 2010). Consequently, an older drug user has been defined by some as a person 'who is 35 years old or older' (see, for example, Boeri et al., 2008 and Atkinson, 2016), even if much research in this area focuses on those 50 years and over. Beyon et al's (2009) qualitative study of the self-reported health status of older drug users in Merseyside, Northwest England, defined an older drug user as aged 50 and over (Beyon et al., 2009) while Capeda et al's (2016) exploration of trajectories of ageing among heroin users of Mexican origin in Houston, Texas included current or former injecting heroin users who were 45 years or more. The stated cut-off point for older drug users is defined as 40 years of age or older in other publications (EMCDDA, 2010). There is currently no agreed or standard definition of an older drug user, possibly reflecting the fact that research is only beginning to examine the complexities of being an older person who has been using drugs and/or accessing drug treatment for a prolonged period.

Internationally, research, as well as existing reviews of literature, demonstrate older drug users to have distinct physical and mental health issues compared to younger drug users (Atkinson, 2016; Badrakalimuthu et al., 2010; Doukas, 2017; Johnson et al., 2017; Matheson et al., 2017). It is estimated that the ageing process among older drug users is accelerated by at least fifteen years, owing to the range of health problems evident in this population (Vogt, 2009, cited by Johnston et al., 2017). Studies in a number of European countries and in the US have uncovered high rates of physical morbidity, including circulatory problems, respiratory diseases, pneumonia, diabetes, hepatitis and liver cirrhosis (Beyon et al., 2009; Roe et al., 2010; Rosen et al., 2008). In the US, Lofwall et al. (2005) compared the health status of older (50-66 years) and younger (25-34 years) patients enrolled in opioid maintenance treatment programmes and found older participants to report significantly higher rates of cardiovascular (53.7% vs. 15.4%), gastro-intestinal (26.8% vs. 3.9%) and bone/joint (53.7% vs. 19.2%) problems than younger participants. Matheson et al's (2017) mixed methods study, which aimed to identify the health care and social support needs of older drug users (age 35 years and more) across Scotland, uncovered a range of physical health problems: 53% suffered from chronic pain and 75% had overdosed at some time in their lives. Other commonly reported physical health problems included heartburn/reflux (50.4%), asthma (27.4%) and high blood pressure (21.1%). Three-quarters of this study's participants were in opiate substitution treatment and over two-thirds (69%) had used hepatitis C services in the past. According to the authors, the health issues facing this group, who had an average age of 41 years, "would be equivalent to people in the general population fifteen years older" (Matheson et al., 2017: 41).

For those with long histories of opioid use, the physical ageing process may be accelerated due to the cumulative effects of polydrug use and associated higher rates of infections and degenerative disorders such as hepatitis and liver cirrhosis. The intersection of drug-related conditions, natural age-related impairments and cognitive functioning make this ageing population increasingly susceptible to adverse health consequences (Grella & Lovinger, 2011; Hser et al., 2004; Torres et al., 2011). Individuals with long drug use histories have also been found to report a range of mental health problems, including psychological and psychiatric comorbidities (Matheson et al., 2017; Rosen et al., 2011). Sidhu et al's (2012) research on the psychosocial characteristics of older heroin-dependent patients (defined as 45 years and over) attending a specialist addiction clinic in Stoke-on-Trent, UK, found that 40% had a diagnosis of depression, 20% a diagnosis of anxiety disorders and 10% a diagnosis of a personality disorder. In Scotland, Matheson et al's (2017) research revealed far higher rates of a self-reported (as distinct from diagnosed) mental health disorders, with 95% of the 123 older drug users surveyed reporting depression and 89% affected by anxiety.

The range of complex physical and mental health problems faced by older drug users and those who are long-term participants in drug treatment are frequently accompanied by social issues and challenges including isolation, loneliness, unemployment and housing precariousness or homelessness (Atkinson, 2016; EMCDDA, 2017; Johnston et al., 2017; Matheson et al., 2017; Roe et al., 2010). Ayers et al's (2012) qualitative study of 20 drug users, aged 55 or over, in Bristol, UK, found that a majority reported feeling shame and embarrassment related to being an older drug user, which led to isolation from family and friends and also prevented them from seeking help with their drug use. Research in the US has also revealed that stigma related to age and prolonged drug use careers is a significant issue faced by older drug and methadone users and can act as a barrier to substance use and mental health treatment (Conner & Rosen, 2008; Smith & Rosen, 2009). For example, Conner & Rosen's (2008) qualitative study of methadone patients aged 50 years and over in a US Midwestern city uncovered the multiple stigmas experienced by this older population of MMT clients. Of those who experienced two stigmas simultaneously, the most common combinations were the stigma of drug addiction and ageing (33%) and the stigma of depression and taking psychotropic medications (25%). Respondents also felt stigmatised for their drug use by the staff at drug rehabilitation facilities where they had attempted to receive treatment. This research further revealed that the personal life histories of participants impacted their ability to trust others, which in turn led them to self-isolate (Smith & Rosen, 2009). To date, research on older or long-term participants in drug treatment points strongly to experiences of social isolation, stigma and shame, highlighting a complexity of needs among this population (Atkinson, 2016; Ayers et al., 2012; Conner & Rosen, 2008; Matheson et al., 2017). According to Atkinson (2016: 31), "[t]he key messages on social isolation and exclusion, shame and stigma are that older people may experience such issues more frequently or acutely than younger counterparts".

Across Europe, data on drug use and the drug treatment experiences of individuals who are older and/or long-term participants in drug treatment programmes is in fact limited (EMCDDA, 2010). While the research base on older drug users has expanded in recent years (Doukas, 2017), it remains patchy, owing to the area-specific nature of much of the research, which limits generalisability, albeit simultaneously contributing to knowledge about

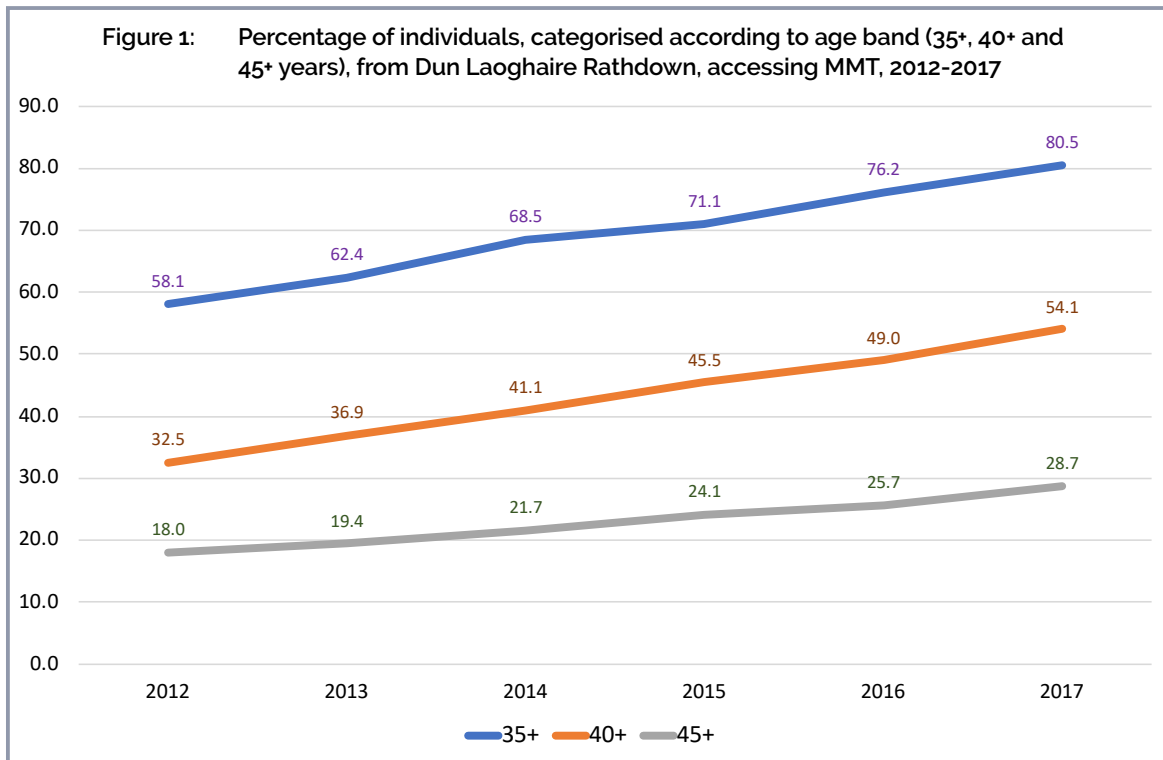
this large and under-researched cohort among the broader drug treatment population. In Ireland, the specific circumstances and needs of older drug users who are accessing treatment has gained recognition (Department of Health, 2017; Health Service Executive (HSE), 2016) but practically nothing is currently known about the health and social needs of individuals who are long-term participants of MMT (HSE, 2016). While previous research in the Irish context has examined the experiences of methadone maintained clients of all ages (Harris & McElrath, 2012; Van Hout & Bingham, 2011), to date, research has not focused specifically on individuals who have been clients of MMT for an extended period.

The Research Context

The research presented in this publication was commissioned by the Dun Laoghaire Rathdown (DLR) Drug and Alcohol Task Force. With the overarching aim of conducting a detailed examination of the experiences of individuals who are long-term participants in MMT, the study recruited individuals attending addiction treatment services in the DLR area who first accessed treatment at least ten years prior to participating in the research. To be eligible for participation, all individuals had to also report at least one episode of opioid substitution treatment (see Chapter 3 for a detailed account of the study's research aims and methodological approach).

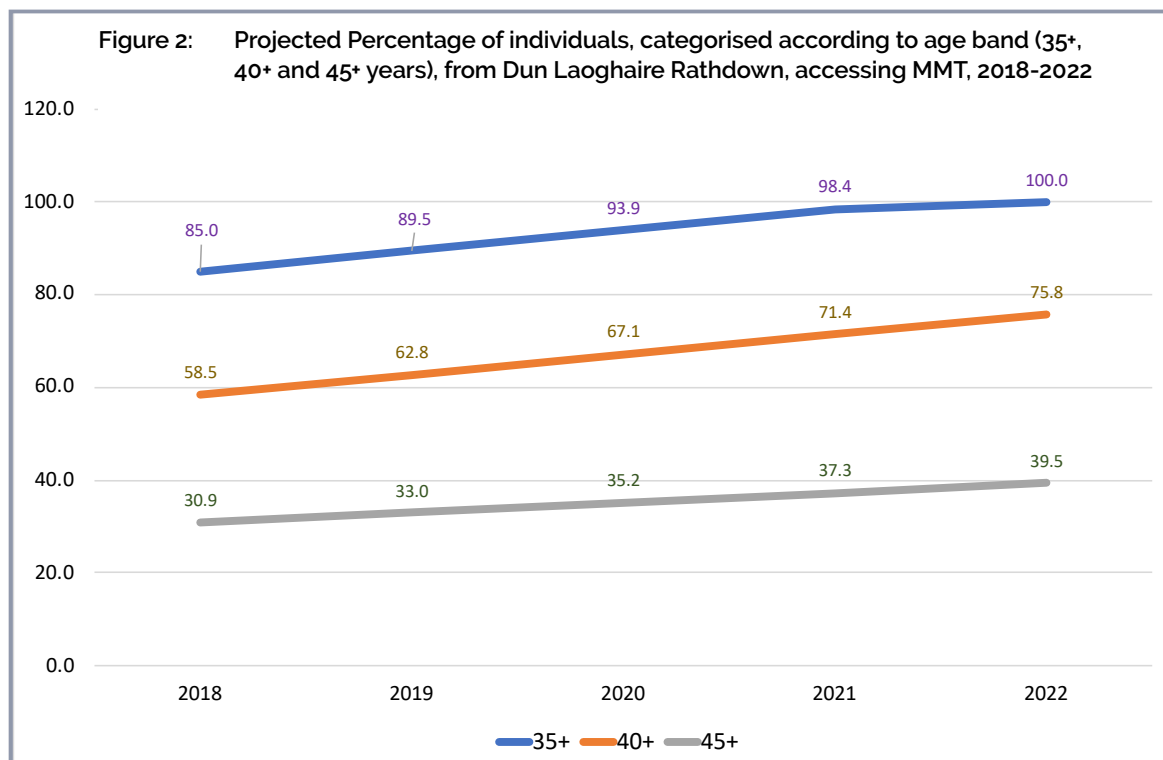
The study site is one of a number in the Dublin region affected by the 1980s/1990s opiate epidemics. Research carried out in 1983 in a central city area of Dublin revealed that 10% of young people aged 15-24 years had used heroin during the previous twelve months, with many injecting the drug daily (Dean et al., 1983). A similar study carried out in the Dun Laoghaire area found that a significant, albeit lower proportion (2.2%), of young people in the same age range were regular heroin users in 1983-84 (Dean et al., 1984). DLR is one of twelve areas (later extended to fourteen) where Drug Tasks Forces (subsequently re-named Drug and Alcohol Drug Task Forces) were established in 1997 to "provide a forum for community, voluntary and statutory services to work together in providing a comprehensive response to opiate addiction" (Keenan, 2002: 3).

Data from the Central Treatment List, which is a complete register of all patients in Ireland receiving methadone as treatment for problem opiate use, indicate that between 2012 and 2017 the total number of MMT clients in the DLR area dropped from 566 to 508. Significantly, as demonstrated in Figure 1, over this same period, the proportion of clients in the age categories 35+, 40+ and 45+ years demonstrates a steady and significant increase.



Source: Central Treatment List Data for Dun Laoghaire Rathdown, 2012-2017

Based on these figures it was calculated that, between 2012 and 2017, the average yearly percentage increase in the number of clients of MMT aged 35+, 40+ and 45+ years was 4.5%, 4.3% and 2.1%, respectively. These percentages were used to calculate the likely composition of the population of clients over the age of 35 years by the year 2022. As the data presented in Figure 2 demonstrate, these projections indicate that, by 2022, 100% of clients of MMT in the DLR area will be over the age of 35 years, 75.8% will be over the age of 40 while 39.5% will be aged 45+ years.



Thus, mirroring national trends, the number of clients in DLR who are older and availing of MMT is increasing and will, according to these projections, continue to increase year-on-year. This geographical area therefore provides an ideal site in which to examine the experiences and perspectives of long-term clients of MMT.

The research is timely in light of a growing recognition, both in Ireland and throughout Europe, of the specific challenges faced by older drug users who are clients of drug treatment (EMCDDA, 2010, 2017; HSE, 2016). In Ireland, the social and health needs of older drug users are recognised and explicitly articulated in the recently published strategy *Reducing Harm, Supporting Recovery – a health-led response to drug and alcohol use in Ireland 2017-2025* (Department of Health, 2017). According to the Strategy:

This cohort is likely to suffer from negative social consequences of long term drug use such as unemployment, social exclusion, marginalisation and homelessness. In addition to conditions associated with the normal aging process they are prone to a range of health-related problems including dental deterioration, hepatic damage, often exacerbated by excess alcohol use, and chronic lung, venous and arterial damage. They are also at risk from harm as result of the interactions between methadone and medications used to treat other diseases (Department of Health, 2017: 44).

One of the Strategy's stated strategic actions aimed at enhancing access to services for this specific population is to "improve the response to the needs of older people with long term substance use issues" (Department of Health, 2017: 47). More broadly, the Strategy recognises the importance of service user participation in the planning, design and delivery of effective services:

Service users, because of their direct experiences of services, have unique insights which are a valuable resource to those involved in developing services and interventions. Facilitating their involvement in the development and design of services is therefore a core objective of drugs policy (Department of Health, 2017: 66).

Internationally, the assessment of patient satisfaction with MMT has been recommended for some time (Bell, 2000; Marsden et al., 2000; Trujols et al., 2012) and research has also documented the importance of patient satisfaction as a predictor of MMT retention (Kelly et al., 2010, 2011; Viallafranca, 2006).

Consumer participation in drug treatment can empower service users and also potentially improve service quality and health outcomes (Rance & Treloar, 2015). Nonetheless, service user involvement has been relatively slow to develop in the drug treatment sector (Fischer & Neale, 2008; King, 2011). In Ireland and elsewhere, client involvement in drug treatment services has been demonstrated to be minimalist or confined to low-level, rather than more meaningful, participation in decision-making (Bryant et al., 2008; King, 2011)².

2) See Chapter 2 for a more detailed discussion of service user involvement in drug treatment.

Organisation of the Report

Chapter 2 provides a narrative review of the evolution of MMT and its management by healthcare systems in Ireland and internationally. In Chapter 3 the study's methodological approach is outlined, detailing the recruitment strategy, data collection methods, data analysis procedures and the ethical considerations that guided the conduct of the research. Chapter 4 is the first of four to report the study's findings and provides a detailed profile of the study's participants, documenting their age, gender, family status, education, employment, drug use and drug treatment histories, current housing situations and histories of homelessness. Participants' experiences of MMT are examined in detail in Chapter 5, which presents their perspectives on methadone, focusing in particular on ambivalence and the clinical experience of MMT. Chapter 6 extends the focus by examining study participants' broader experiences, including employment and perceived barriers to labour market participation, their social and family relationships and the experience of stigma, all of which are relevant to understanding social reintegration. Physical and mental health are the primary focus of Chapter 7, which also examines study participants' service utilisation practices and their perspectives on 'recovery'. Chapter 8 concludes by discussing the key findings to emerge from the research.



CHAPTER 2

Reviewing the Evolution of Policy on Methadone Maintenance Treatment and its Management by Healthcare Systems

This chapter reviews relevant Irish and international research and policy literature, as well as 'grey' literature and media coverage, of drug dependence and its management by healthcare systems. Rather than simply summarising research findings, the intention here is to shape this material into a narrative that can be used to inform the analysis and presentation of findings arising from the research. The aim, therefore, is not to focus narrowly on the technical or 'evidence-based' aspects of addiction treatment but to look more broadly at how addiction continues to be a highly contested concept, reflecting ongoing cultural conflict and moral ambiguity about the use of psychoactive drugs and societal management of drug-related problems.

Irish drug policy has developed since the 1960s (Butler, 2002a) in the shadow of relevant United Nations (UN) conventions. These international conventions evolved throughout the twentieth century, heavily influenced by the religious temperance ethos of the United States of America (Bewley-Taylor, 2001; Gusfield, 1986) and strongly of the view that illicit drug use is a self-evident moral evil, the management of which should rest primarily with the criminal justice system. In circumstances where criminal justice systems pursued a 'war on drugs', the role of healthcare systems has not, however, always been clear. Nonetheless, by the 1970s, radical differences between British and American policies on this issue (Mars, 2012; Strang & Gossop, 1994) had virtually disappeared and the dominant view was that healthcare workers should support their criminal justice colleagues by working exclusively towards the goal of abstinence, that is, getting people drug-free. Against this background, a recurrent theme in this review is that of the 'normality' of addiction treatment within healthcare; specifically, what is in question is the extent to which addiction is seen as a normal disease and individuals with an addiction problem are seen as normal patients, deserving and receiving the same respect and care as others in receipt of medical treatment. Social scientists (Becker, 1963; Cohen, 2002; Reinerman & Levine, 1997) have long been critical of popular cultural and media representations of drug users, arguing that such representations consistently exaggerate the threat posed by drug use to the moral and social order. A related strand of sociological critique deals specifically with stigma (Goffman, 1963; Lloyd, 2013), a reference to the way in which some groups of people (for example, problem drug users) experience themselves as marked out as deviant, socially unworthy and generally the subject of negative public opinion. The degree to which health service interventions, such as methadone maintenance, succeed in challenging the idea that these service users

are just 'addicts' whose views and beliefs do not deserve to be heard is of obvious concern to the present study.

Permeating this review of the literature are two core themes: the first relates to health service tensions between abstinence and harm reduction models of care and, the second, to the place and role of service user consultation and participation in policy and service delivery.

Abstinence versus Harm Reduction

Irish Policy Background

The fact that Ireland's Misuse of Drugs Act made such leisurely legislative progress (being recommended in 1971, enacted in 1977 and 'commenced' in 1979) indicates the relatively static nature of the country's drug scene in the 1970s; illicit drug use throughout this decade remained of low prevalence, with 'soft' drugs predominating and little or no injecting opiate use (Butler, 2002a). All of this changed from 1979 onwards with the advent of what epidemiologists referred to as the 'opiate epidemic', a reference to the emergence of a serious injecting heroin use problem in Dublin (Dean et al., 1985).

Prior to this, the healthcare response to drug problems had been based in one centralised medical facility, the National Drug Advisory and Treatment Centre at Jervis St. Hospital, Dublin which, while under the direction of a consultant psychiatrist, was not part of the mainstream adult mental health service. From 1973 onwards, individuals with an addiction problem could also avail of a voluntary, American-style residential service, Coolmine Therapeutic Community (Butler, 2016). This original service provision was based upon two, largely implicit, assumptions: 1) that primary care/community services had nothing to offer and that addiction treatment was best provided in specialist centralised services and; 2) that abstinence was the only valid goal of treatment – in other words, clinical interventions should aim at getting individuals drug free and keeping them drug free. These assumptions were quickly called into question by the scale of the new heroin problem and, even more dramatically, by the identification in the early 1980s of a new virus, the human immunodeficiency virus (HIV). Those infected by HIV were at high risk of developing a full-blown condition, acquired immune deficiency syndrome (AIDS), which attacked the immune system and left its victims prey to a range of life-threatening infections. It was quickly ascertained that one of the main modes of transmission was through the sharing of injecting equipment amongst drug users; in addition to infecting one another through the sharing of injecting paraphernalia, the fear from a public health perspective was that drug users might also – through sexual contact – act as a 'bridge' for transmitting HIV to non-drug-users.

To a large extent, therefore, HIV/AIDS acted as a catalyst, both in Ireland and elsewhere, for the widespread introduction of health service interventions under the rubric of harm reduction. These interventions were based on a pragmatic acceptance that, for a majority of drug users, traditional abstinence-based services were ineffective and that, in the prevailing circumstances, it was imperative that drug users who could not or would not commit to abstinence should be assisted to use drugs in a way that minimised the risk of HIV infection.

Butler and Mayock (2005) argued that while Ireland introduced a range of harm reduction initiatives from the mid-1980s onwards, what distinguished it from other countries such as the UK (Strang, 1998) was the unusually surreptitious style of such policy change. In the main, and almost certainly reflecting political concerns about public hostility to such measures, harm reduction practices in Ireland were implemented quietly, with minimal public debate or official announcement of this quite radical policy change. The idea that service provision should be centralised was also challenged by epidemiological research on heroin use in inner-city Dublin (Dean et al., 1983) which presented its findings in public health terms, identifying environmental (poverty, poor housing, educational disadvantage, family dysfunction and early involvement in crime) rather than individual risk factors as of primary causal importance in the genesis of serious drug problems. These research findings suggested, at least implicitly, that preventive and treatment initiatives might be more usefully deployed at localised or community level in these high-risk neighbourhoods. It was not until 1996, however, that this public health argument was fully accepted, when the First Report of the Ministerial Task Force on Measures to Reduce the Demand for Drugs (colloquially the 'Rabbit Report') (Ministerial Task Force on Measures to Reduce the Demand for Drugs, 1996) created Local Drugs Task Forces, structures that were intended to target resources at identified high-risk neighbourhoods and would facilitate collaboration between local community/voluntary bodies and statutory health services.

In 1998, following a protracted but low-key policy process, the Misuse of Drugs (Supervision of Prescription and Supply of Methadone Regulations), S.I. No. 225 of 1998 – commonly referred to as the Methadone Protocol – was signed into law (Butler, 2002b). Effectively, this statutory instrument created a licensing system for General Practitioner (GP) prescribing of methadone and contained a number of other safeguards that were intended to promote good clinical practice whilst simultaneously avoiding the diversion of prescribed methadone into the black market.

Methadone Maintenance

Methadone, a long-acting synthetic opiate developed in Germany in the 1930s as an alternative to morphine, was initially used as a short-term medication for the detoxification of opiate-dependent patients. Paradoxically, given the evangelical commitment to abstinence models of addiction treatment in the US, the idea that methadone could be used as a long-term opiate substitute for heroin addicts emanated from American doctors. During the 1960s, Marie Nyswander (a psychiatrist) and Vincent Dole (a physician), both based at the Rockefeller Institute in New York, introduced and evaluated the use of methadone as an indefinite substitute for street heroin. For Nyswander, who had previously viewed addiction as symptomatic of underlying personality difficulties for which psychotherapy was the treatment of choice, this medical model of heroin addiction represented a radical change of perspective (Courtwright, 1997). Dole and Nyswander continued to promote the use of indefinite methadone maintenance (with the drug usually being taken orally once daily) as a practice that retained patients in treatment, reduced relapse to street heroin use and generally allowed its users to have a relatively healthy, socially stable and crime-free life (Dole & Nyswander, 1965; 1976).

Half a century after Dole and Nyswander's pioneering work, methadone maintenance

continues to be a controversial issue, about which there is ongoing public suspicion and political unease. On the one hand, there is robust research evidence to support its value in reducing drug-related health and social harms (see Chapter 1); on the other, there is ongoing criticism of its use on the basis that it is a cynical, oppressive practice favoured by the state – with the connivance of the medical profession – that traps users of the substance into a lifelong and stigmatising addiction.

On the positive front, there has always been research evidence to support the value of MMT. In 1998, when the Irish authorities were introducing the Methadone Protocol, a group of Australian researchers (Ward et al., 1998) published a review of the research literature, which – while not presenting methadone as a panacea – was extremely positive about its capacity to retain patients in treatment and deliver good health and social outcomes for its patients. Furthermore, these researchers concluded that the evidence favoured indefinite rather than time-limited maintenance and high rather than low-dose prescribing. Over the intervening years there has been considerably more evaluative research on addiction treatment outcomes, including several large-scale, national longitudinal studies – such as National Treatment Outcome Research Study (NTORS) in England and Wales, Drug Outcome Research in Scotland (DORIS) and Drug Abuse Treatment Outcome Study (DATOS) in the US – all of which have broadly endorsed the value of methadone. In Ireland, the ROSIE study (Comiskey et al., 2009) followed 404 opiate-dependent adults entering a range of services, reporting improvements in health and social functioning for all treatment modalities studied and commenting specifically on methadone clients as follows:

It was observed that 38% of the participants recruited in methadone were still in their treatment intake setting at 3-years. Research suggests that retention in methadone treatment is associated with more positive outcomes (Lawless and Cox, 2001) and the findings presented here are very encouraging for methadone treatment services, particularly given that, at 3-years, it was observed that 59% of those interviewed were currently receiving methadone treatment (Comiskey et al. 2009: 11).

Finally, a Cochrane Collaboration study (Mattick et al., 2009) found that methadone maintenance was more effective than other forms of treatment in retaining clients in treatment and reducing heroin use, although it was not found to have a significantly better impact than other treatments in terms of mortality or criminal activity.

Nonetheless, many researchers have been reluctant to attribute positive outcomes in a mechanistic way to any type of formal treatment intervention, pointing out that it would be prudent to take wider contextual factors into consideration before rushing to causal judgement. For instance, the British researcher, Gossop (2005), sounded this caution when commenting on the lessons to be learnt from these large-scale longitudinal studies:

Interventions taking place during treatment are just part of a much wider range of factors that can influence outcome. In many cases, treatment may be neither the most important nor the most powerful influence upon outcome. Environmental supports and stresses can influence outcomes. Peer and family relationships, unemployment and living arrangements can all have an important effect. The gains produced by an effective treatment programme can be undermined or neutralised by adverse social and environmental factors (Gossop, 2005: 10).

On the question of continued methadone prescribing for ageing patients, there is relatively little specific literature (Carew & Comiskey, 2018) but, as some Swiss researchers have

pointed out, in practice 'there is no age limit for methadone' (Dürsteler-McFarland et al., 2011). At present, therefore, there is no evidence-based suggestion that long-term clients ought to be persuaded or coerced into a methadone-free life. Finally, prescribers are understandably cautious about detoxifying their methadone clients since relapse into street drug use is common even for those ostensibly committed to abstinence (Ducray et al., 2012) and such relapse carries with it a risk of fatal overdose (HRB, 2017). In this context, it is particularly relevant to the present study that Darke (2014), in his review of the international research literature on opioid overdose, points out that it is older drug users whose general health status is poor – rather than young inexperienced drug users – who are most at risk of overdose.

Recovery

It would be erroneous to suppose that methadone maintenance – particularly long-term or indefinite maintenance – is an uncontroversial practice based upon scientific consensus and enjoying popular and political support. In Ireland, as elsewhere, over the past twenty years there have been regular criticisms of methadone from the media, religious authorities, community activists and various stakeholder groups, generally reflecting the view that long-term maintenance is a cynical and morally dubious medical practice. Such criticisms (Irish Times, 2014; O'Brien, 2007; Walsh, 2000) depict methadone as a 'government drug' that traps its victims with 'liquid handcuffs' and condemns them to lifelong addiction to an unpleasant drug that is as bad, if not worse, than street heroin. Another recurring criticism of methadone prescribing in locally-based addiction treatment clinics as opposed to GP settings is that these clinics and their clients become focal points for anti-social behaviour that is disruptive to business, tourism and everyday community life (Evening Herald, June 30, 2014).

From about 2008 onwards, populist criticism of this kind became increasingly reflected in policy discourse as a number of countries (including the UK and Australia), which had previously favoured harm reduction, moved towards what was referred to as a 'recovery' approach to healthcare management of drug addiction (Best et al., 2017; Lancaster et al., 2015; McKeganey, 2014). The term recovery is ill-defined and contentious but, arguably, is best understood as an ideological backlash against methadone maintenance and a return to the ideals of abstinence – presumably not unrelated to the fact that HIV/AIDS had, by this time, become a chronic but manageable, rather than an acute and potentially fatal, condition. This resurgence of abstinence-based approaches to addiction treatment has not been based upon demonstrably improved outcomes of abstinence-based treatments. As Berridge, writing from a historian's perspective on the 'rise, fall and revival of recovery in drug policy', has noted: "Recovery is a term redolent of 19th century temperance" (Berridge, 2012: 22).

At a political level, methadone maintenance has often created uneasiness. In Ireland, for example, Fianna Fáil, had indicated during 1996 that it did not approve of indefinite methadone prescribing and that it would create a time-limited methadone regime, a proposal which it quietly dropped once in government (Butler, 2002b). In the UK, political disquiet based on a belief that addicts were being left on methadone for longer than was necessary resulted in a request from the government in 2014 to the Advisory Council on the Misuse of Drugs (ACMD) to consider the potential for introducing time-limited maintenance.

ACMD responded with two reports, which rejected the suggestion that individuals were being 'parked' on methadone, citing evidence that time-limited methadone maintenance would add to a wide range of negative health and social consequences. Furthermore, ACMD, while expressing support for the aspirations underlying recovery policy, commented on the practical difficulties in achieving positive outcomes for clients who – quite apart from their opiate dependency – were multiply deprived:

Evidence shows that those with heroin dependence had a greater likelihood of having life problems prior to dependence than those with dependence on alcohol or other drugs. A heroin-using lifestyle was associated with significant collateral damage including high rates of premature death; for survivors, physical and mental health problems, criminal records, unemployment, poor housing, damaged relationships were likely. Therefore recovery is a highly ambitious goal for those with heroin dependence. It is asking individuals not only to overcome dependence but also to achieve positive outcomes in health, social and economic functioning that some have never previously had – all the while trying to manage the consequences of significant collateral damage (ACMD, 2015: 7).

In responding to similar disquiet, Irish policy makers opted to use the term 'rehabilitation' rather than 'recovery'. A major initiative took place in 2007 with the publication of an official report on this topic, which arose ostensibly from a public consultation process in relation to the then National Drugs Strategy (Department of Tourism, Sport and Recreation, 2001). The necessity to have a specific 'rehabilitation pillar' in the strategy was explained at the beginning of the report:

The need for a rehabilitation element to the overall Strategy was a recurring theme during the consultations and was seen as essential in ensuring that drug users are not kept on methadone indefinitely (Working Group on Drugs Rehabilitation, 2007: 6).

Following the publication of this report, implementation of its recommendations proceeded slowly; a framework document (Doyle & Ivanovic, 2010) was drafted three years later and, four years after that, an evaluation of a pilot scheme (Barry & Ivers, 2014) was completed. The detailed schemes proposed in Irish policy documents for the rehabilitation of individuals accessing addiction services were largely reliant on cooperation from a wide cross-section of public sector agencies outside of the health system, including those concerned with criminal justice, housing, education and training, income maintenance and child and family welfare. However, the development of these rehabilitation proposals coincided with the breakdown of a series of 'cross-cutting' drug policy structures that had been in place since the Rabbitte Report of 1996 (Butler, 2007). This meant that the health sector could not presume upon enthusiastic collaboration from other governmental sectors and agencies in its implementation of the ambitious rehabilitation framework. Furthermore, following the publication in 2006 of the mental health policy document, *A Vision for Change* (Department of Health and Children, 2006), it was clear that the public mental health services were increasingly reluctant to accept responsibility for the management of addiction.

Cloud & Granfield (2008) have developed and elaborated the concept of 'recovery capital', which refers to the array of personal and social resources necessary to facilitate and maintain recovery from a severe drug dependence. Probably few would disagree with the aspiration

to help individuals with a heroin addiction to become drug free, while simultaneously enjoying full social reintegration; however, as they are currently structured and resourced, Irish addiction services do not have the capacity to provide the recovery capital necessary to support this aspiration. Perhaps it should come as no surprise then that, despite the prominence of the 'rehabilitation' theme in Irish drug policy, there has been no reduction in the numbers of clients in receipt of methadone, with data from the Central Treatment List showing that about eleven and a half thousand clients were in official receipt of methadone during the year 2017³.

Consulting Drug Service Users

The suggestion that the views of addiction service users should be elicited and taken into consideration, both in relation to their own treatment and in relation to wider policy and service provision (Fischer et al., 2007), is broadly in line with similar thinking in healthcare generally and in the wider public service (Branfield et al., 2006). The core notion, in New Public Management terms, is that service users should be seen as 'customers' who are routinely consulted about what they want and how satisfied they are with what they actually receive. Such an approach to addiction treatment had begun to be challenged even before New Public Management ideas became prominent; in the UK, Edwards (1989) suggested that the advent of HIV and the introduction of harm reduction philosophy and 'user-friendly' service provision meant that clients were becoming more able to secure treatment on their own terms.

Obviously, health service user involvement of this kind presents a challenge for healthcare professionals, previously accustomed to a situation in which they were regarded as having a monopoly on wisdom and expertise and in which the 'patient' assumed a largely passive role. The application of this new thinking to addiction service users has been especially problematic given traditional attitudes towards a client group viewed, historically, as manipulative, untrustworthy and – from a conventional medical perspective – non-compliant (Fischer & Neale, 2008). The power imbalance inherent in all professional-lay interactions was particularly acute, therefore, in relation to addiction treatment in Ireland, as elsewhere. Since the millennium, however, Irish drug policy documents have regularly recommended service user participation, with the most recent National Drug and Alcohol Strategy (Department of Health, 2017: 67) stating:

Service user involvement is about facilitating people to become meaningfully involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating policies and in planning, developing and delivering services, and in taking action to achieve this.

Similarly, the clinical guidelines for opioid substitution treatment published by the Health Service Executive in conjunction with the Irish College of General Practitioners, the Irish College of Psychiatry and the Pharmaceutical Society of Ireland (HSE, 2016: 11) describe

3) Data obtained from the Central Treatment List, which is a register of all patients receiving methadone in Ireland, indicate that between 2014 and 2017, more than 11,000 individuals were receiving methadone each year, with the figures increasing slightly year-on-year (from 11,206 in 2014 to 11,496 in 2017). Between 2011 and 2013, the total number in receipt of MMT remained under 11,000 (10,711 in 2011, 10,832 in 2012 and 10,951 in 2013).

service user involvement as follows:

Involving service users as active partners in their drug treatment is essential and is associated with better outcomes. Service users should be fully involved in the development of their care plans, setting appropriate treatment goals and reviewing their progress in treatment. It is also good practice to involve service users in the design, planning, development and evaluation of services, and in advocacy and support groups linked to local services.

By and large, however, empirical research has found little evidence that Irish drug treatment services have taken on board these recommendations. King (2011: 283), who conducted a qualitative study of methadone provision in an urban setting, concluded: "The principal finding of this study was that the policy rhetoric of service user involvement was not matched by the reality of service provision in the drug treatment systems investigated here". Both service users and service providers interviewed for King's study were of the view that service user participation existed only in a minimal, tokenistic way, with methadone clients treated as passive service recipients in a system where their views were neither sought nor considered of any value. Van Hout & McElrath (2012) explored a similar theme in relation to the potential of service user forums to involve clients in addiction treatment programme developments in a rural area, but again found that the rhetoric of service user participation was not matched by actual events and experiences. Studies of service users' experience of GP methadone treatment in Ireland (Latham, 2012; O'Reilly et al., 2011) have reported satisfaction with individual prescribing practices but a more general feeling that the potential for greater service user participation – as reflected in policy statements – was not being realised.

These research findings are broadly similar to those of other Irish and international studies (Conner & Rosen, 2008; Fraser 2006; Fraser & Valentine, 2008; Harris & McElrath, 2012; Neale, 1998; Van Hout & Bingham, 2011). Indeed, the findings of several qualitative studies make it clear that, whatever the research evidence of the value of methadone maintenance at a population health level, the subjective experience of its clients – particularly those on long-term maintenance – is at best ambivalent but more commonly negative. While methadone clients frequently acknowledge the benefits they derive from MMT, they do not as a rule see themselves as 'normal' health service users who are availing of legitimate, evidence-based medicine. Instead, a dominant theme is one of continued stigmatisation, in which they feel marked out for public opprobrium with few opportunities to express their own point of view or influence the course of their clinical management. The title of one American paper – "You're nothing but a junkie" – which examined the experiences of stigma in a sample of older adult methadone maintenance clients (Conner & Rosen, 2008) – captures these ideas vividly. There are some specific issues that arise commonly in the course of these largely negative portrayals of life on methadone maintenance, including perceived difficulties in discussing a dose reduction and/or the possibility of detoxification with prescribers; complicated negotiations around the subject of take-away doses; feelings of stigma arising from supervised urine testing and taking the drug under supervision, particularly in a community pharmacy; and the negative attitudes of methadone clinic staff. In general, the views of methadone users, when asked for their views in a research context, mirror and amplify critical social science views of the stigma that has long been associated with illicit drug use (Lloyd, 2013).

Conclusion

Addiction to illicit drugs continues to be a marginal and contentious issue, with 'ownership' of this 'problem' poised ambiguously between healthcare and criminal justice systems. To the extent that addiction is regarded as an illness or disease, its management within healthcare systems is still shrouded in moralism insofar as it is commonly seen as a self-inflicted condition so that its sufferers cannot claim the kind of sympathetic response that might be expected were they to present with other illnesses. A related complication for healthcare management of addiction arises from the ongoing stigma attached to the condition, which results in its clients being viewed as more criminal, devious and threatening than other patients, with perceptions of this kind making it difficult to 'normalise' their treatment. In this context, it should be noted that the status of addiction treatment within the Irish healthcare system is, in organisational terms, decidedly marginal; having been explicitly repudiated by mental health and never fully accepted within primary care, it is consigned to 'social inclusion'. In 2017, more than 60% of those in receipt of MMT were clients of specialist addiction clinics rather than GP surgeries.

It is also important to note the multiple difficulties of an economic and psychosocial nature associated with, and often preceding, opiate dependency. Those who become long-term methadone patients do not, as a rule, have the recovery capital to overcome their dependence nor has the health system the resources to manage the various problems and needs – associated with housing, employment, criminal justice contact, education and training – of its addiction patients. Neither is there any guarantee of a sympathetic response in this regard from other governmental sectors and agencies.

Finally, and in relation specifically to methadone, there are some obvious complications that may be identified from the literature reviewed here. For those working in methadone services, whose training and education in harm reduction and in other aspects of addiction treatment may have been quite minimal, there may well be an awareness or suspicion that what they are doing is less worthy or useful than it might be, particularly since official policy for the past decade has extolled the virtues of recovery. Just as mental health professionals worked for decades in institutions, which they were constantly told were outmoded and obsolete, those working in MMT services may nowadays be under a similar impression that their work with this particular client group is less important and more morally questionable than work being undertaken in under the umbrella of 'recovery/rehabilitation'.

In conclusion, the work of Fischer & Neale (2008) on the difficulties facing British services in implementing service user participation initiatives has obvious relevance to the Irish scene. If Irish services are to move beyond what is largely a minimalist and tokenistic approach to this issue, it must be recognised that policy rhetoric needs to be accompanied by increased resourcing for 'recovery capital' in dealing with this highly deprived client group and by a more concentrated programme of education and training that can challenge and change the historic prejudice and stigma still attached to these clients.



CHAPTER 3

Research Methods

This chapter provides an account of the study design, which privileged respondents' lived realities as long-term participants of methadone maintenance treatment programmes. It outlines the research aims, recruitment process and the approach to interviewing research participants. The chapter discusses the ethical considerations and procedures that guided the conduct of the research and documents the data analysis procedures.

Study Design

The study, which is qualitative, was designed to examine the experiences and perspectives of individuals who are long-term participants in MMT programmes. As outlined in Chapter 1, the research was undertaken in the Dun Laoghaire Rathdown area of South Dublin, where concentrated drug problems have been recorded since the 1980s opiate epidemic. The core research objective was to examine client perspectives on methadone treatment, with particular attention directed to the lived experience of MMT, participants' social relationships and their health and social care needs.

A recent study of long-term opiate/methadone substitution treatment, which examined the experiences of individuals maintained on opiate substitution treatment, defined 'long-term' as a period of five years or more (Notley et al., 2015). In order to capture the experiences of individuals who might be potentially older and with long-standing contact with MMT programmes, the current study extended the treatment period to a minimum of 10 years. To be eligible for participation, individuals had to be over 18 years and:

- 1) have accessed drug treatment for the first time at least 10 years prior to participating in the study and;
- 2) report at least one episode of opioid substitution treatment since they first accessed treatment.

Access and Recruitment

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 recruiting clients of specialist addiction services, which comprise a mix of larger addiction centres and satellite clinics (Farrell & Barry, 2010). Drug users who attend the larger addiction centres are often more 'chaotic' than those attending satellite clinics (Department of Health and Children, 2005) and both of these groups would generally be expected to have less stability in their lives than clients of MMT who attend primary care settings. Older drug users who attend clinics may have long-standing and complex needs associated with the duration of their treatment and may also confront particular challenges related to employment, housing precariousness and homelessness.

Contact was made with service professionals, including managers, GPs and front line workers, to inform them about the study aims and how they might assist us in making contact with individuals who met the study's eligibility criteria. Meetings were arranged with service managers and GPs, who were provided with a detailed information sheet designed to communicate the research aims and what the participation of their service or GP practice would involve. In other cases, phone conversations were arranged with relevant service professionals and the information sheet was sent to them by email. We received a high level of co-operation from professionals, who distributed information about the study and arranged for us to meet with individuals who expressed an interest in participation. A separate information sheet, also given to the study's 'gatekeepers', was designed for prospective research participants, who were aware of the research aims at the point of meeting with a researcher. Prior to conducting the interview, the researcher provided a detailed verbal account of the research and what participation involved, including the kinds of topics that would be discussed during the interview. Participants were informed that they could decline to respond to any question that they preferred not to answer and it was also explained that they had the right to withdraw from the study at any time, even after completing the interview. The study's confidentiality and anonymity protocols were clearly outlined to participants who were encouraged to ask questions and to seek clarification on any issue. All participants signed a consent form prior to taking part in the interview.

Twenty-five clients of MMT were recruited to the study between August 2017 and February 2018 and, of these, 16 were male and nine were female. Thus, broadly mirroring the total clinic population (HRB, 2018), approximately twice as many males as females were recruited to the study. All interviews were scheduled in consultation with participants who nominated a time and location of their choice to meet for interview. A majority of the interviews were conducted in a local service setting (n=16), with fewer taking place in the homes of participants (n=6), a café (n=2) or in the office of the researcher (n=1). With participants' consent, all interviews were audio recorded. The interviews lasted for between one and two hours, with a majority ranging between 60 and 80 minutes in duration. Participants received a €25 gift voucher as a token of appreciation for their time.

The Conduct of In-depth Interviews

The in-depth interview was used to explore a broad range of issues deemed relevant to understanding participants' experience of MMT. All interviews commenced with the open-ended question, 'Can you tell me a bit about your life at the moment?'. This question was

designed to encourage participant comfort and to give respondents control over the issues that they deemed relevant in that moment. Following this opening question, several topics were targeted for discussion, including: current living situation and housing; education and employment history; drug use and drug treatment history; experiences of drug treatment; any difficulties or set-backs experienced; everyday life (daily routines, family and social relationships); physical and mental health; perceived social and health care needs and; perspectives on the future. While strong attempts were made to address all of these topics with each respondent, this aim was balanced with flexibility in responding to and capturing personal perspectives and stories (Fraser & Valentine, 2008; Neale, 1998). Thus, while the interview was topic-centred, it was fluid in structure (Mason, 2018) and, throughout, respondents were encouraged to speak openly and to discuss their views and concerns. Service users' experiences and perspectives were therefore at the core of the research interview which sought to elicit detailed accounts of the lived experience of long-term MMT.

Following the conduct of the in-depth interview, a brief questionnaire was administered to record demographic details for each participant as well as data related to housing, education, employment/sources of income, family (number and age of children and where they resided) and physical and mental health. This questionnaire was administered to aid the construction of a detailed sample profile.

Ethical Considerations Guiding the Conduct of the Research

Illicit drug users are frequently identified as a 'vulnerable' population requiring 'special protection' in the context of research. Discussions in the literature include debates about the ethics of researching marginalised populations, the use of incentives and capacity to give informed consent among other issues (Aldridge & Charles, 2008; Fisher et al., 2008; Murdoch & Caulfield, 2016; Seddon, 2005; Souleymanove et al., 2016). Many people whose lives include problematic substance use or addiction have experiences marked by challenging circumstances that may include trauma, loss and individual and structural violence or abuse (Bourgois & Schonberg, 2009; Etherington, 2007). Equally, research with so-called 'vulnerable' populations indicates that many individuals consider participation to be a positive experience because it allows them to tell their story which some feel may benefit others (Richards & Schwartz, 2002; Sutton et al., 2003). Nonetheless, since qualitative research relies upon the sharing of sensitive and potentially painful experiences, several steps were taken to ensure that the dignity and well-being of the study's participants was safeguarded.

As outlined earlier, all participants were provided with full and detailed information about the research – including the study's confidentiality and anonymity procedures – prior to giving their written consent to participate. It was also made clear that declining to participate would have no negative ramifications of any kind and, in particular, for their continued participation in treatment. Specific procedures and techniques aimed at protecting research participants were also adhered to during the interviewing process. Importantly, while participants were encouraged to speak freely and candidly, they were also advised that they were not obliged to answer all questions posed. During the interview, new topics or areas of questioning were

'flagged' with participants in advance rather than introduced abruptly and interviewers also asked the respondent if s/he was comfortable to discuss the topic in question. Perhaps most importantly, a perspective of wanting to learn from participants was communicated and maintained, empathy was displayed and moments of both sadness and humour acknowledged and responded to by the interviewers. Ethical approval for the conduct of the research was attained from the Research Ethics Committee, School of Social Work and Social Policy, Trinity College Dublin.

Data Analysis

All interviews were transcribed verbatim, checked for accuracy and coded using the qualitative data management software NVivo. Analysis followed a 'grounded theory' approach (see Charmaz, 2006), which is inductive in orientation, meaning that categories and sub-categories emerged from the data rather than determined a priori. Following a thorough review of the transcripts, 17 coding categories were used to organise the data into more manageable 'chunks' (Miles et al., 2014). A 'case summary' was also prepared for each participant, documenting key issues related to their drug use and drug treatment histories, experiences of MMT, their views and perspectives on MMT and the meanings participants attached to methadone and recovery. The case summaries helped to ensure that the analysis was contextualised, located in participants' broader life experiences, thus permitting relevant contexts to come into focus in the production of a situated analysis (Mason, 2018). Throughout the data analysis process, counting was used to ensure the identification of dominant patterns in the data and deviations from those patterns (Seale, 1999). Finally, thematic analysis, which is useful for characterising the key features of a qualitative data set (King, 2004), was used to identify, analyse and organise significant patterns within the data (Braun & Clarke, 2006). This method of analysis is effective when seeking to examine "the perspectives of different research participants, highlighting similarities and differences, and generating unanticipated insights" (Nowell et al., 2017: 2).

Data from the questionnaires was entered to an Excel file, coded, and subsequently imported to the Statistical Packages for the Social Sciences (SPSS) programme. This assisted the generation of an overall descriptive sample profile.

Importantly, each participant was assigned a pseudonym and all possible identifiers, including the names of family members, friends, service professionals and places (neighbourhood locations, the names of services accessed) removed from the data. As a further measure to protect the anonymity of participants, an age range rather than precise age is used throughout this report, alongside the pseudonyms attached to the narrative excerpts presented.

Conclusion

From the outset, this research was committed to garnering service user perspectives on long-term MMT. Whilst mindful of the potential vulnerability of those individuals who agreed

to participate in the study, respondents' capacity for decision-making and their agency was recognised and respected. The data analysis process involved coding and counting, procedures that increase the reliability and credibility of interpretive accounts (Seale & Silverman, 1997), and thematic analysis was used to identify salient patterns in the narratives of study participants. The analysis presented in the chapters that follow aims to produce a detailed and nuanced account of the experiences of individuals who are long-term participants in MMT.



CHAPTER 4

Sample Profile

This chapter provides an overview of the study's sample. Demographic details of those individuals who participated are first provided, followed by the presentation of profile data on their education, employment status and income, drug use histories, entry to methadone maintenance treatment, current substance use and housing and homelessness. These data offer an important contextual backdrop for the analyses presented in later chapters.

Demographic Profile

Sixteen of the study's 25 participants were male (64%) and nine (36%) were female. The average age for the sample was 43 years; eight were between 35 and 39 years (a majority of them 37 years old or more), 14 were aged 40 to 49 years and the remaining three were aged 50+ years. All participants were Irish and of white ethnicity.

At the time of interview, most participants (n=19) were single, with just six stating that they were currently in a relationship. A majority (n=18), including nine women and nine men, had children. Over half had one or two children (n=10) and the remaining participants were parents to three (n=6) or four (n=2) children. Participants' children ranged in age from three to 26 years. Of the 18 parents, nine (including six women and three men) were living with their children. Four participants (all male) stated that their children were living with their mother; the child of one participant (a male) was living with grandparents and the child of another (a male) was in foster care. Three children were adults and living independently.

Education

The educational attainment of participants was generally low. Six had no formal educational qualifications, having left the education system either shortly after or during their primary level schooling. More than half (n=13) had progressed to Junior Certificate level before leaving secondary education for a range of reasons, including to take up employment (n=6), due to expulsion (n=2), upon learning of a pregnancy (n=2) or because of problems related to addiction (n=2) or homelessness (n=1). Just one participant had progressed to Leaving Certificate level, while a small number of others (n=3) had obtained a third-level certificate (n = 3). One participant had returned to education as a mature student and obtained a postgraduate degree.

Employment Status and Sources of Income

At the time of interview, only three participants – all female – were employed full-time. The vast majority (n=21) were therefore reliant on social welfare payments. The types of payments that participants received included Jobseeker's Allowance (JA) (n=9), Disability Allowance (n=7) and Community Employment (CE) Scheme payments (n=5). Those in receipt of a CE Scheme payment, which is marginally higher than the JA rate of payment, attended a training and employment course five days weekly at a community-based rehabilitation service.

Drug Use Histories

The average age of drug initiation for the study's participants was 14.2 years. Three participants recalled using solvents as early as 10 or 11 years but, for more than half (n = 13), the drug of initiation was cannabis. Drug use was almost always described as commencing during early adolescence in the company of peers in locations in, or in close proximity to, their home neighbourhoods. A large number described a rapid progression to polydrug use. The most commonly reported drugs of use during this period of early drug experimentation were ecstasy, cocaine and hallucinogens.

"I was, say about 13, I was hanging around with blokes 16 and 17 and they were going, starting to go to jail and we were going into visit them and you'd bring them in a parcel, but you'd keep a little bit [of cannabis] back for yourself and then you'd have a few joints. It started off with the bit of hash and then it went on to the acid and the mushrooms and then for a few years it was the acid and the mushrooms and then it was the ecstasy." (Richie, age 40-44).

One participant reported her drug use as beginning with benzodiazepines before transitioning to polydrug use. However, there were others who did not report the use of multiple substances before initiating heroin use, with four stating that they had little or no prior drug use experience. Two participants had used cannabis only and one had consumed cocaine and ecstasy just occasionally before experimenting with heroin for the first time at the age of 28 years. Street-sourced physeptone was the first substance used by two participants while one male stated that he began using heroin in his mid-twenties in order to curb a problematic pattern of alcohol consumption.

The average age of initiation to heroin use was 19.1 years for the sample. Almost half (n=12) experimented with heroin for the first time between the age of 14 and 17 years; eight tried the drug for the first time between the age of 18 and 22 years while five were between the age of 24 and 30 years when they initiated use. Thus, almost half of the study's participants (n=12) began using heroin during the period 1990-1995, coinciding with the second opiate epidemic in Dublin (O'Gorman, 1998). Of the remaining participants, six initiated use between 1996 and 2000, four during the 1970s or 1980s and just two more recently, between 2000 and 2006.

A majority of participants (n=15) initiated heroin use by smoking, with a smaller number

(n=7) stating that they injected the drug at the point of initiation. The remaining participants consumed opiates for the first time in synthetic form or via nasal inhalation. The vast majority (n=21) had injected heroin during their lifetimes, with only four reporting that they had never used the drug intravenously.

Entry to Methadone Maintenance Treatment

The average age of first entry to a methadone maintenance treatment programme was 23.8 years for the sample. The largest number of participants (n=11) were between the age of 21 and 25 years at the point of first accessing treatment, with six being younger, aged 20 years or under. The remaining eight participants were aged 26-30 years (n=4) or 30-35 years (n=4) when they entered into treatment for the first time. Of the study's 25 participants, 16 had first accessed treatment more than 20 years previously.

The circumstances surrounding first entry to MMT varied for participants. Several stated that the decision to access treatment was influenced by significant others in their lives, including their parents (n=5), children (n=3), other family members (n=2) or friends (n=1). Leanne explained that her parents insisted that she get help at the age of 15 years.

"... I wasn't going into treatment for myself, I was going in because my Ma was having enough." (Leanne, age 40-44)

Two female participants reported that they had entered into MMT initially in order to supply methadone to a romantic partner.

"I feel I only went to the clinic because at the time he (partner), like, would have been buying more methadone and his thing was, 'Ah you don't really need it', and he'd take my weekend bottles like." (Bernie, age 40-44)

However, for most participants, entry to MMT was a decision that they made independently, often at a point when their lives had become unmanageable and their health had deteriorated.

"I was tired, worn out. I wasn't eating, my health was declining and my weight was (pause), I looked like I was going to drop. My life was in tatters, I just wanted help." (Cormac, age 35-39)

"I didn't want to be doing heroin anymore. I'd just seen the effects of it on other people, you know, people you see in the city centre. They're so bad they're walking round like ghosts and shit like that. They're just ... I was going, 'I'm not going to end up like that.' And I went to [city-centre clinic]." (Chris, age 35-39)

For others, entry to MMT was linked to wanting to avoid withdrawal symptoms and/or to sustain employment.

"Well, because in work you're lifting heavy equipments and you went into work and you were sick, you just couldn't cope. And I needed the help." (Danny, age 40-44)

It is noteworthy that three participants referred to the introduction of the Methadone Maintenance Protocol in 1998 as having significantly restricted the availability of street-based methadone, leading them to enroll in treatment in order to access the substance.

"I had no choice but to go into treatment because the Protocol came in ... The first clinic I was ever sent to was (clinic based in city-centre). Scary place, that was a scary place." (Catherine, age 40-44)

Current Substance Use (Including Methadone)

At the time of interview, the vast majority of participants (n=22) were taking a daily dose of prescribed methadone. The average daily dose for the sample was 65.1 mgs. Eleven participants were on a daily dose of between 50 and 100 mgs, six were below 50 mgs, while five were on a daily dose above 100 mgs. The highest daily dosage reported was 135 mgs and the lowest was 2mgs. Two participants reported that they were abstinent from all drugs, including methadone, for six and seven years, respectively.

Most participants reported the current use of at least one substance apart from methadone. Some were using a single drug, including heroin (n=2), benzodiazepines (n=5) or cannabis (n = 3). Others reported the use of a combination of drugs, including heroin and benzodiazepines (n=3) or cannabis and benzodiazepines (n=2). Six participants stated that they were not currently using any substance apart from methadone while one participant did not disclose information about their current use of substances (apart from methadone).

Housing and Homelessness

Current Housing Situations

At the time of interview, participants' housing situations varied, as demonstrated in the data presented in Table 1.

Nine participants lived in either local authority housing or housing provided by an approved housing body. The vast majority of these participants (n=6) were females with children in their care. The reported duration of living in local authority housing ranged from less than six months (n=1) to more than ten years (n=2), with the remaining participants (n=4) stating that they had lived in their current local authority property for between two and seven years. Both participants who lived in housing provided by an approved housing body had moved to those properties only a number of months prior to interview.

Two participants, both female, lived in private rented sector accommodation at the time of interview; one was paying rent independently with earnings from full-time work while

Table 1: The Current Housing Situations of Study Participants

Housing Type	Male	Female	Total
Local Authority Housing	2	5	7
Approved Housing Body	1	1	2
Private Rented Sector	0	2	2
Home of Family Member	5	0	5
Privately Owned Home	1	0	1
Moving between homes of family members and partner's family	1	0	1
Transitional Homeless Accommodation	6	1	7

the other was renting with the support of the Rental Accommodation Scheme (RAS). Five participants, all male, lived in the home of a family member and, of these, three lived with a parent(s), one with two siblings and one lived alone. At the time of interview, one participant was moving between the homes of his partner and a family relative, which is a situation of 'hidden' homelessness, and another was living in a privately owned home inherited from his parents.

Finally, seven participants, six of them male, were living in transitional homeless accommodation, having experienced a period of homelessness before taking up residence in that accommodation. The reported duration of time spent in transitional housing varied, with three stating that they had lived there for a relatively short period of between one and three months. A further three had lived in transitional housing for more than one year and the remaining participant for a period of between three and six months.

Experiences of Homelessness

Over half (n=14) of the study's participants, the majority of them male (n=10), had experienced homelessness at some point in their lives. Accounts of homelessness varied but most had spent periods sleeping rough (n=9) and/or had accessed emergency hostel accommodation (n=12). Many of these participants also reported periods of 'hidden' homelessness, that is, staying temporarily with friends and/or family members (n=6). One participant reported that she spent the entire period of her homelessness, which extended over a period of more than two years, living in emergency Bed and Breakfast (B&B) accommodation with her two children. This woman was currently living in local authority housing.

The reported duration of homelessness also varied. Three participants had experienced intermittent homelessness for lengthy periods of between 15 and 20 years while the remaining participants reported a single period of homelessness. For most, these periods were lengthy, spanning more than five years (n=2) or between two and three years (n=4). A further four participants had experienced homelessness for less than one year. Discharge from prison and a lack of appropriate accommodation upon release was a key factor in the experience of a period of homelessness in the case of five participants.

"When I first got out of prison I was homeless, there was nothing in place for me ... And they had me in a hostel in town there and it's just them hostels in town. Like they're just, you have to be sleeping with one eye open ... so I'd rather sleep rough. I was sleeping in cars." (Dillon, age 35-39)

Very frequently, experiences of homelessness coincided with periods of chaotic drug use and the loss of accommodation. Explaining that family members "had to turn their back on me", one participant subsequently spent a period of more than six months moving between hostels and rough sleeping.

"That was a crazy time in my life, yeah, yeah, yeah ... Well you're in the height of your addiction and you don't really care as long as you can get your head down and get in and out of the wind and get into the warm." (Ronnie, age 45-49)

While all who experienced homelessness had accessed hostels in the city-centre, five participants reported a prolonged period of rough sleeping in their home neighbourhood, most often in parks or secluded wooded areas. Homelessness was invariably depicted as a traumatic experience. Participants often described emergency hostel accommodation as threatening and dangerous and as exposing them to high levels of drug use as well as new licit and illicit drugs and/or modes of administration. Several stated that they had, on many occasions, opted to sleep rough, feeling that it was a safer alternative to homeless shelter accommodation.

"First I was going into hostels, but there's just too much drugs, people are robbing you blind ... I went in to have a shower, came out, caught someone going through my stuff ... Looking through all my stuff, you know what I mean, money, everything with me. And said, 'I'm not going through all this.' So I started sleeping on the streets." (Danny, age 40-44)

Conclusion

The profile presented in this chapter includes several markers of social exclusion for the sample as a whole in the form of experiences of homelessness and insecure accommodation, inadequate education, poor employment skills and low income, all of which are closely associated with problematic drug use (Keane, 2007; March et al., 2006). Equally, unemployment, poor employment prospects and homelessness among drug users can undermine treatment gains (EMCDDA, 2012). Abstaining from or reducing drug use can present significant challenges if an individual does not have access to supportive structures such as stable housing, as well as opportunities to (re)engage with education and to secure and sustain employment.



CHAPTER 5

The Experience of Methadone Maintenance Treatment

This chapter documents respondents' experiences of, and perspectives on, MMT. As outlined in Chapter 2, methadone and other opioid substitution treatment occupies an ambivalent place in the lived experiences of many individuals in treatment (Fraser, 2006; Fraser & Valentine, 2008; Harris & McElrath, 2012; Radcliffe & Stevens, 2008; Smith, 2010). Ambivalence also emerged as a prominent theme in the narratives of this study's participants, even if a majority recounted ways in which methadone had, and continues to have, a beneficial impact on their lives. A core aim of this chapter is to unravel the nature and complexity of what many participants presented as primarily negative experiences of MMT despite acknowledging one or even multiple benefits. The chapter starts by presenting an overview of participants' treatment regimes at the time of interview.

Methadone Dosage, Urinalysis and Takeaways

At the time of interview, the vast majority of participants (n=22) were taking a daily dose of prescribed methadone⁷. Dosages ranged from 2 to 135 mgs, with half (n=11) reporting a daily dose of between 50 and 100 mgs. Five were consuming above 100 mgs daily and six below 50 mgs. Of these 22 participants, 19 attended a clinic and three a primary care setting. Over half (n=12) attended a clinic or primary care practice either weekly or more often than weekly while three participants attended on a fortnightly basis. Seven – all currently living in homeless accommodation – attended a clinic daily and, of these, six were dispensed and consumed methadone on-site, while one attended a pharmacy daily.

Seven participants were required to provide urine samples on a weekly or twice weekly basis, three provided a sample once fortnightly and five once monthly or infrequently. Three participants were not required to provide urine samples while four (three of them women) stated that they refused to provide supervised urine samples to their prescribing doctor. Catherine, who had provided urine samples under supervision for many years, explained her reasons for refusing to do so more recently.

7) It is important to note that a large number of the study's participants use the term 'phy' – which is an abbreviation for physeptone – when they referred to methadone. While physeptone was the first opiate or opiate substitute drug used by a number, this was not in fact the case for a majority of participants. It appears, therefore, that the use of this street term or colloquialism has endured among the opiate treatment population.

"You know, I think just because a woman of a certain age who has had children – I haven't committed a crime, I'm not a drug mule. Why am I sitting in a toilet with mirrors? And I think when you're at a certain stage that your doctor knows, you don't bullshit him – you know, like, if I've used – I'd tell a doctor I'd used. You know? Unsupervised is not too bad but I just don't like giving urines at all." (Catherine, age 40-44)

Of the study's 22 participants who were current clients of MMT, nine attended a clinic on a daily basis where all but one consumed their daily dose (one attended a pharmacy daily). Thirteen participants reported takeaway arrangements, which meant that their visits to a clinic/primary care practice and pharmacy were less frequent. Of these, four visited a clinic and pharmacy two or three times weekly and a further six had weekly takeaway privileges. The remaining three received their takeaways to last two weeks. All participants, including those who attended a clinic daily and those who had been granted a takeaway arrangement, were required to consume their daily or initial dose of methadone (in the case of those in receipt of takeaways) under supervision at either the clinic or pharmacy.

The transition from clinic-only attendance for MMT to a combination of clinic and pharmacy visits or, alternatively, to GP and pharmacy attendance was invariably welcomed and viewed positively by participants. For many, this transition marked a milestone, often depicted as a reward for 'good behaviour', meaning that they had demonstrated the ability to provide 'clean' urines.

"On a chemist, you could be every day but I'm on it only once a week so that means you're doing brilliant." (Deirdre, age 35-39)

"The doctor is putting me back on takeaways soon because I'm doing well again ... because I'm not taking any tablets or anything. I'm just stable on my methadone." (Tommy, age 40-44)

A number also made reference to a shift, equated by them with being perceived as reliable and trustworthy by their prescribing doctor and, therefore, deserving of a greater degree of freedom and flexibility: "(Doctor) got me on to the chemist ... eventually I was seen as trustworthy" (Eric, age 35-39). The drug use and treatment histories of participants who had 'graduated' to takeaways were diverse and the vast majority reported that they had temporarily lost that privilege at particular junctures along their treatment paths. Takeaways were valued by participants for the release they provided from the far more restrictive routine of daily clinic/pharmacy visits; they also had personal and symbolic significance related to feeling trusted and having earned more respectful treatment. The significantly fewer number of appointments or attendances required to access methadone was also seen by a number as reducing the risk of being 'seen' and publicly identified and labelled as a methadone patient: "When you're on the clinic you're with all the other people that are on the clinic" (Catherine, age 40-44). Conversely, the consequences of providing 'dirty' urines were severe, as Cormac explained.

"Dirty urines, you know, I'd be back on dailies, my takeaways would be taken off me, you know what I mean? And the implications on your life like" (Cormac, age 35-39).

Methadone, Stability and Normality

A majority of the study's participants reported that methadone treatment had impacted their lives positively in at least one respect. These accounts focused on three major positive ramifications, the most commonly stated benefit being that methadone brought stability and normality to their lives. These accounts typically referenced change in relation to everyday life and activities which, for some, led to a renewed sense of purpose. Ronnie, who first accessed MMT in the late 1990s, told that he had come to accept that he "just needs" methadone and went on to explain that methadone had transformed his life.

"And look where it (methadone) led me ... it led me to good places ... and getting some real stability in my life and being able to be useful again in society and in the community because I did do a lot of damage as an addict in the community."
(Ronnie, age 45-49)

Focusing on the time and 'space' created by MMT, Chris similarly emphasised change, referring specifically to the insights he had gained into his abilities and what he could potentially achieve in the future.

"Changed my life for the better like, you know. Being on methadone and stuff like that, it's made me realise a few different things like, things I can do and things I can't do and you just have a lot of time to think." (Chris, age 35-39)

For others, stability meant that they could engage more positively with their families and children and take responsibility for everyday tasks that had previously presented significant challenges. These participants emphasised their greater ability to fulfil their roles as family members and/or parents.

"That's the one good thing about methadone is you're stable, you can have somewhat of a normal life, you know ... I like the stability of methadone, I can just engage in family life, have a sup of tea and watch programmes and just have a chat. Because before, I'd just stay in my room because I'd probably be stoned." (Eric, age 35-39)

"Yeah, it's (methadone) kind of settled me. I found that I was better at the house and better looking after the kids and more settled ... 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)

Stability meant not having to find ways to procure drugs on a daily basis which reduced stress levels dramatically and supported the transition to a more conventional lifestyle. Some participants also noted that their financial situations had improved dramatically.

"I'm doing alright because I'm not buying drugs or anything. So now I'm waking up on Monday morning with fifty quid in my pocket and that's great ... I have money in the bank and in the credit union. I've never had that before." (Richie, age 40-44)

A second significant benefit highlighted by male participants in particular was one associated with stability but related specifically to a reduction in criminal activity and criminal justice contact. For Stephen, "normal" functioning meant less "strife" because he no longer had to steal to finance his drug use.

"Yeah, it's (methadone) very beneficial – you've less fucking strife in your life, it brings a bit more normality back into your life. You can function normally without fucking robbing a shop just to get a fix." (Stephen, age 40-44)

Craig, who considered himself to be stable on methadone, having not relapsed in more than eight years, reflected on his life before and after methadone. Reporting a lengthy history of criminal justice contact spanning from adolescence as well as multiple periods of incarceration, he considered that his life had changed.

"The way I look at it is that it's better than me going out robbing four, five or six houses a night and that's what I used to have to do and then getting caught eventually, getting took away from my kids, terrorising people around my area and everything else that comes with it (heroin use). I'm changed now." (Craig, age 35-39)

The third significant issue raised by respondents related to the perceived health benefits of MMT. As outlined in the previous chapter, participants in this study had frequently accessed treatment at a point when the quality of their lives had deteriorated dramatically; heroin use, and the demands of securing a supply of the drug to avoid withdrawal symptoms, had also taken a serious toll on their health. Participants noted improvements in their health, sometimes contemplating what may have transpired had they not engaged in treatment.

"Maybe the maintenance did save my life? I don't know? Maybe if I had kept using drugs I probably would have HIV now – 'cos I have hepatitis C – I could have full blown AIDS. I could be dead, I probably would be dead." (Craig, age 35-39)

Like Craig, others referred to death, noting that methadone "probably saved my life" (Kevin, age 55+) or "I might be dead now" (Ronnie, age 45-49). Bernie had been taking methadone for more than 20 years and, throughout her interview, was critical of many aspects of MMT. However, when questioned about any positive aspect, she responded by noting that she "would have died years ago" had she not enrolled in a treatment programme.

[Is there anything that has been good about methadone for you?]
"Well I suppose, if I didn't, I would have died years ago because I would have used more – and knowing that you're not going to have that horrible sickness and that – and that you can fall back on your phy – that's the only thing that I can think of." (Bernie, age 40-44)

Participants' accounts of the perceived benefits of methadone focused, in the main, on some element or elements of transformation in their lives, often associated with a release from the demands of illicit drug use and the introduction of stability and normality. Methadone was depicted by some as having enabled the restoration of family life and relationships and, by others, as having removed the need to constantly seek ways to fund heroin use. For males,

in particular, accessing methadone treatment marked a decline in criminal justice contact. Irrespective of gender, improvements in health were noted by participants, who frequently directly referenced possible consequences – including death – had they not engaged with MMT.

Exploring Ambivalence

As stated at the outset of this chapter, ambivalence about MMT emerged as a dominant theme in the narratives of the study's participants. While acknowledging some or several benefits, a complex constellation of negative perspectives were recounted. This section seeks to unpack this ambivalence, which focused heavily on the control that methadone was perceived as exerting over participants' lives. Temporality was at the centre of these accounts; over time, clients of MMT increasingly questioned methadone's role and place in their worlds and, when they anticipated the future, very many expressed anxiety, apprehension and even anger about what potentially lay ahead.

The accounts of Chris and Richie illustrate the tensions that were embedded in a majority of accounts of MMT. Both men acknowledged (now) "needing" methadone, with Richie describing it as a "comfort blanket" and Chris explaining, perhaps more judiciously, that he had merely substituted heroin with methadone "to try and be normal".

"It's (methadone), it's probably one of the worst things I took, out of all the drugs, it's probably the worst. The taste of it is horrible, the feeling in your stomach. Now, it IS a comforting feeling because I know I need it ... I need it now, like I know I need it and it's just like a comfort, a comfort blanket." (Richie, age 40-44)

"I mean I'm glad I actually have it (methadone) but, I mean, like quality of life is only in that perspective. I'm just using a different drug to try and be normal." (Chris, age 35-39)

As documented in the previous section, the achievement of stability and normality was the primary perceived benefit of methadone. Yet this positive consequence of engaging with MMT was almost always juxtaposed by a characterisation of methadone as constraining or controlling core functions, with attention frequently directed by participants to the suppression of emotions and a general inability to move forward with their lives. Dillon described methadone as "stalling" but not "fixing" the problem, depicting methadone maintenance as a "place" where progress, in terms of the achievement of broader social and personal aspirations, did not materialise for most.

"... but like the phy (methadone), it's only stalling the problem, it's not fixing it. It's only just keeping it at a certain stage, it's not getting any better, you know what I mean. 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)

Dillon's reference to MMT as a "holding" space was expressed – albeit in different ways – by several others. At the core of these narratives was a perceived absence of a path, with a large number conveying a sense of being 'stuck' or trapped in a cycle that did not lead to progress or change. For Yvonne, a mother who attributed her vastly improved family situation and relationships to MMT, methadone represented a "ball and chain", its meaning tightly bound to stagnation.

"It (methadone) represents to me a ball and chain, a ball and chain. Liquid handcuffs we like to call it. To me it represents stagnant, no change." (Yvonne, age 40-44)

Referring to the "daily grind" of attending the clinic, Conor also used the term 'liquid handcuffs' when he discussed the routine of MMT.

"... and then it starts again – Friday, Saturday, Sunday, Monday, Tuesday – then attend (the clinic) on Wednesday. So, twice a week go to the chemist. But it's taken me years to get to that stage, years to get off the daily grind of every day, right? But the reality is that it's like liquid handcuffs. You're chained to that..." (Conor, age 35-39)

He went on explain that he understood the context and rationale for the introduction of MMT but asserted that it left 'addicts' with no choice. Conor's reference to the term "lifer" is revealing as it highlights a perceived inevitability of MMT as unending.

"It shouldn't happen, to be honest with you, it shouldn't happen. I understand the AIDS thing and all and that they needed to come up with something. But it just put it on ice, it did, and now it's, it's fucking being abused. In the worst way. It's left addicts with like, with no choice ... you go on methadone and you're a lifer then, you know." (Conor, age 35-39)

Embedded in these accounts were references to the constraints that methadone imposed, which had symbolic as well as material significance. Bernie, who felt "hostage" to MMT, described a routine of being "oiled up" in order to start her day.

"But like, it's like you're held hostage by this green substance ... and you don't even know what's in it like. How can I say it feels? Like the Tin Man out of the Wizard of Oz that has to be oiled up every day. Like, to me, methadone is like you take it before the start of your day. Like the Tin Man has to take his oil before he starts his day." (Bernie, age 40-44)

The 'Tin Man' image is a powerful one, used by Bernie to convey the enduring bind of the daily dose. One of 16 participants who first accessed MMT more than 20 years previously, she also expressed concern about the long-term health consequences of methadone consumption.

"What's the outcome? I have this fear because we're the first generation that would be showing signs of what the phy (methadone) is doing inside like, you know. The doctors and stuff don't know because we're the first generation and that's scary like." (Bernie, age 40-44)

Like many others, Chris talked about "the serious lack of freedom" imposed by MMT while Richie likened MMT to a life of confinement.

"... it's not a life. You're not alive, you're just like (pause) ... it's like being, it's like I'm still in prison. I have to go and collect my phy (methadone) every morning ... I can't do anything, like, I can't plan anything because of it." (Richie, age 40-44)

When responding to questions about the experience of MMT, women, in particular, talked about their mental health, highlighting the numerous challenges they faced, often associated with anxiety and depression but also with a significantly diminished sense of purpose, self-worth and self-esteem.

"I feel like my personality is dying. I feel like the methadone is turning me into a drone, a methadone drone." (Catherine, age 40-44)

"It's like it (methadone) weighs you down, like mentally and physically." (Bernie, age 40-44)

Participants who were no longer taking methadone and those on a low daily dose also spoke in negative terms about the impact of methadone on their mental health. Rachel, who was drug free, recalled what life was like when she was taking methadone, referring to the sense of hopelessness she felt during that period.

[Like how did it feel being on methadone?]

"Nothing, just numb ... I just felt worthless, helpless, hopeless, nothing. It was awful. Just a lack of everything, a lack of confidence, a lack of self-esteem, a lack of everything ... I really felt worthless, you know." (Rachel, age 40-44)

Kevin was clear that MMT had "saved" his life but also felt that methadone had dulled his emotional world.

[So has methadone been a good treatment for you?]

"Well I would have to say it's been a mixed bag. There's no doubt it saved my life. Yeah, even improved my life ... But, by the same token, it made me very emotionless. As I'm coming off it now I'm becoming much more emotional again. And that meant that I wasn't much bothered about (sexual) relationships ... and I think that's what methadone does, I think it kills the emotional centre. Not dead but it dulls it." (Kevin, age 55+)

Describing his life as "stable", despite ongoing struggles with anxiety linked to what he described as "the life I led", Seán explained his perspective on methadone as 'harm reduction'.

"People say that methadone is a safe drug, it is in terms of, you know, I suppose they call it harm reduction, isn't that the term they use? But for people like me there was no such thing as harm reduction. I think it's a psychological thing, if I'm being honest with you, it's not the fact that the methadone is causing you any sort of physical damage. I think it's just, it's causing you psychological damage." (Seán, age 50-54)

As respondents related their experiences, they tended to focus strongly on the present. However, most also talked about the future, often articulating a sense of the unknown. While very many wanted to escape the routine of methadone treatment, these participants also frequently expressed doubt about whether that aspiration could ever be realised. References to growing older – accompanied by questions and anxieties about the future – featured centrally in these accounts.

"I've been on it (methadone) for that long. Ok, I've worked but a lot of it has been drugs, drug, drugs. And I know there's more to life out there than drugs ... I don't want to be 50, 60 years old on methadone." (Danny, age 40-44)

"When I was young I never thought I'd be on methadone 'till I was forty. I remember seeing people walking around and I'd be saying to myself, 'Ah no, I am never going to be that old taking methadone.'" (Leanne, age 40-44)

"Well I always thought that it (methadone) was going to be a temporary thing ... I never envisaged it as being as long as it is and I'd say I'm going to be on it for the foreseeable future. I just can't see a (pause) ... anything changing. A lot of just cynical anger sometimes." (Lorraine, age 40-44)

One participant who was drug-free offered her insights on MMT and the risk that long-term clients of drug treatment may be "forgotten".

"Just a bit of insight – that, you know, you don't have to stay on methadone, there is a way out of it, you know. Where people are on methadone for 20, 30 years, just don't forget them like because you see that a lot of time ... the ones that are on it 20 years are kind of forgotten about because it's like, 'Ah, there's no hope for them!'" (Rachel, age 40-44)

The perspectives documented here – located in the experiences of study participants – bring the meaning of methadone in their lives into sharp focus. Participants recounted numerous ways in which methadone shaped the fabric of their worlds, both socially and emotionally, particularly with the passing of time. Their views and perspectives – situated in the present but clearly constructed over time – are critical in allowing an understanding of the facets of stagnation and control, as well as a perceived loss of emotional well-being, enmeshed in the experiences of this study's long-term clients of MMT.

The 'Culture' of the Clinic: "It's not asking 'what do you think?'"

While participants' accounts focused strongly on the impact of methadone, as substance and 'substitution', on their everyday lives, a majority also identified a host of issues associated with the clinical experience of MMT. These critiques focused primarily on the regime or 'culture' of the clinic rather than on individual professionals even if, at times, particular relationships and interactions were specifically noted. This distinction between individuals and the 'system' is quite critical in that participants frequently noted interactions and relationships with professionals (along their treatment paths) that were positive and

enabling whilst simultaneously delivering quite pointed critiques of the treatment system in general. Several, for example, stated that they had a good or constructive relationship with their GP and/or with other professionals working in the clinics they attended. Alvin described his prescribing doctor as “helping him”, explaining that gradually reducing his daily dose – a personal desired aim – was “my own plan with the doctor”. Richie said that he felt supported by his GP while Stephen reported: “My doctor is good, funny as well and supportive”. Some respondents mentioned both treatment settings and doctors who they felt were compassionate and willing to discuss and respond to their needs.

“Like s/he’s very good, the doctor. I can talk to the doctor, you know, if you have a problem or anything ... I have a good relationship with my doctor ... Now, I mean, well, s/he knows obviously what’s going on, and would say like, ‘What’s going on or is there something up with (daughter)’? Or, you know, kind of knows if I’m really stressed. S/he’s great now, the doctor, my methadone doctor.” (Ciara, age 40-44)

“I feel supported, absolutely, yeah, yeah. The one thing about my doctor is s/he’s very methodological and very, you know, ‘Now, are you sure?’ and I’d be, ‘Yeah, yeah, I’ve had a good think about it’ ... so wonderful support there.’ (Ronnie, age 45-49)

A number of participants also spoke positively about other professionals with whom they interacted, including pharmacy staff, nurses and General Assistants (GAs) in the clinics they attended⁸. Christine, for example, was very grateful to the staff in the pharmacy: “The girls in the chemist are so good to me. They don’t even acknowledge me (meaning that they don’t single her out or treat her differently), and not letting anyone see me”. Providing urine samples under supervision was possibly the most frequently cited negative experience reported by study participants (see later in this section). However, a number noted and appreciated ways in which some staff members in the clinic they attended tried to make the experience more manageable.

“There’s one of them (GAs), keeps on trying to talk to me and all and he’s only like, he’s just trying to be nice, you know, and he’s a decent bloke and he tries to talk to me and have a conversation, ‘How are you getting on?’, and all ... And I’m like, ‘Shut the fuck up! (laughs). But it’s all, yeah, you get used to it after a while ... Most of them are alright up there like.” (Richie, age 40-44)

A large number of participants in this study had attended multiple drug treatment services and clinics, both locally and in city-centre locations, and were therefore experienced and very familiar with the drug treatment system. Having navigated these services over a prolonged period, they were also well versed on the environment or ‘ethos’ of various drug treatment settings. It is perhaps significant that a number noted what they regarded as progress, based on their experiences of interacting with treatment systems and professionals over many years. For example, while Seán was critical of the methadone treatment system in a general sense, he recounted more positive experiences in recent years: “I have to say that

8) General Assistants (GAs) perform a variety of roles in addiction specialist addiction clinics from portering through to the supervision of urine collection (Pilling & Hardy, 2013).

(some doctors) are pretty progressive but, for a long time, I would have been of the opinion that doctors wanted you strung out". Another participant commented on some observable attitudinal shifts since she first accessed treatment more than twenty years previously.

"I was on methadone and physeptone such a long, long, long time that I've seen a change in the way people view addicts and, in the chemists, that they're more treated like human beings nowadays, more so than you were back then." (Rachel, age 40-44)

The accounts of participants who recounted positive or improved experiences of treatment tended to emphasise the quality of their relationships with health and other professionals and, in fewer cases, of feeling some degree of ownership over their treatment plan. Compassionate 'moments' or interactions with clinic staff were noted and appreciated, as were attempts on the part of professionals to engage with them personally or make simple gestures that left them feeling respected. One participant recalled a brief but meaningful encounter with a staff member outside the clinic environment.

"Actually, I have to point this out – a (clinic staff member), one day ... I had started to clean myself up and that and I met him outside of the clinic, actually, and I'd never kind of met them before out on the street so I expected he'd pass by and that, but he stopped me and he says, 'You don't mind if I say something to you?' And I said, 'No, go ahead.' And he says, 'You have to look after yourself' ... and he said a couple of other things to me but, when I walked off, the penny dropped later, what he was talking about. It's just something that he said just changed something inside of me, you know. It didn't come from a doctor. What he said changed me so it really impacted me. And it didn't come from a doctor with a PhD, it just came from one of the staff, from you know, from his experience ..." (Ronnie, age 45-49)

However, for the sample as a whole, accounts of the clinic and associated methadone dispensing systems were often negative, highlighting practices perceived by participants as undermining their autonomy and ability to 'have a say' in their treatment. A detailed analysis of these narratives uncovered three key themes that permeated participants' accounts: *lack of care, dehumanising experiences* and *diminished autonomy*.

The following excerpts from Rachel's interview provide considerable insight into the kinds of issues raised by very many participants. Rachel's drug use began at the age of 13 with cannabis, solvents and LSD. She was introduced to opiates via street-sourced physeptone, which quickly progressed to daily use. Rachel told that she was "hooked" on physeptone by the age of 15/16 and started to smoke heroin around that time.

She first accessed treatment at the age of 17 and, from that point, continued to use methadone for the next 16-17 years of her life. Her treatment comprised MMT as well as numerous attempts at detoxification. At the time of interview, Rachel was drug free for six years, having gradually reduced her daily methadone dose over a lengthy period of time.

Rachel, age 40-44

"It's like just walking into the walking dead. You walk in and it's like a clinic and there's a fella standing there to watch over the lads taking a urine and there's a woman there to watch over the woman taking a urine and you go in and see the doctor, s/he writes you out a prescription and you go over to the, you'll either go to the chemist and collect it or they'll dispense it there and then, you know ...

... the real demoralising part, it wasn't the only demoralising part of active addiction, by the way, there's many parts of it that's so demoralising, what you have to do ... (pause) but, and excuse the way I say this, but I used to say that it's so demoralising to go in and you're just like you're pissing in bottles and grovelling to your doctor and grovelling to the chemists and that was your life, that was my life, you know. And then I had this other part of me that just wanted to be out there and working and earning money and having a new apartment and a new car and all this kind of great stuff going on but, yet, I was in the dirt down there with the shackles of methadone...

... because every time you give a urine and it's got heroin in it or tablets or anything like that like s/he'll (doctor) say to you like, 'You can't be coming in here getting methadone off me and using at the same time, it's not the way'. So it was always that kind of thing where you're like you just can't do that like, you know, but you're sort of stuck in a cycle of, 'But I can't stop, you know ... "

Lack of Care

A large number of respondents depicted the treatment experience as instrumental rather than caring, often describing their interactions with health professionals as focused solely or primarily on the substitute drug or 'script'. Encounters with prescribing physicians were brief and did not, in the main, incorporate discussion of their broader personal and social circumstances or any issues or challenges they may be facing.

"The methadone doctors, they don't really care. They don't really wanna know. They listen to what you say but they don't really listen, you know. And if you've a real problem, 'Well go and tell your GP, don't tell me.'" (Yvonne, age 40-44)

"Now don't get me wrong, there is nice people that work in the clinic ... But they're just kind of getting the job done, that's it. Like, not much interaction or anything. It's just literally like, 'Here for your methadone, there's you're script, go over there, do that, do your urine, bye'. That's really the way the clinics are." (Rachel, age 40-44)

Rachel's comment on the lack of interaction was mirrored in the accounts of many others, who described limited communication and the absence of a dialogue of listening and responding.

"You're just going in for your methadone like so you're not really, you know, you're not talking about anything and you're not interacting. You're just going in for your methadone." (Ciara, age 40-44)

This lack of interaction was perceived as demeaning and, for Alvin, more difficult to “unravel” as he grew older.

“You’d say, ‘Look doctor’ (and the doctor would reply), ‘There you go, there’s a script’. And you’re spoken to like you’re dirt so you just toe the line and you live with it. Like you don’t know how to deal with your emotions, I suppose. When you’re young and coming up and you’re angry and you get that attitude but it’s hard to unravel all that as you get older.” (Alvin, age 40-44)

Some participants felt they were treated with indifference and insensitivity within a system which, in the experience of one participant, “lets people down”.

“They don’t care, they just write their prescription and you really feel that. You really feel lost when you’re on that clinic and the methadone and the whole system is just, it really lets addicts down, you know ... like what are they giving people but just them clinics? They let people down.” (Cormac, age 35-39)

The issue of trust was mentioned frequently by respondents as significantly impacting their relationship with health professionals. To a large extent, trust was a reward for good behaviour, strongly connected to providing ‘clean’ urines. While accepting that trust had to be earned, participants nonetheless struggled with the constant demands of gaining and maintaining the trust of their prescribing doctors. A further issue was that this trust could be abruptly withdrawn, which had implications for the granting or continuation of certain privileges, particularly those related to takeaway doses.

“... the doctor will let it be known that s/he just doesn’t trust you ... If your urine was dirty s/he’d say, ‘Either go to the (larger) clinic or I’m cutting you down to such and such.’” (Rachel, age 40-44)

“I think I gave one dirty urine and the doctor was saying, ‘Oh, I don’t think this is going to work out, I think we just have a personality clash and I think you’d be better off on a (larger addiction) clinic.’” (Leanne, age 40-44)

“Yeah, giving urines about three times a week, two times a week, one time a week ... My doctor would say, ‘If you’re not clean in two weeks, that’s it, you’re back on dailies.’” (Chris, age 35-39)

The kinds of interactions described by Rachel, Leanne and Craig were characterised by Seán as perpetuating an “us and them” divide.

“There is very much an us and them sort of thing ... My attitude towards the doctors would have been really fucking negative. You’re a number, you go to the chemist, you know, you’re just a commodity, you know. They give you the script, you go to the chemist and they give you the methadone ... It is like you’re a commodity.” (Seán, age 50-54)

These accounts have many complex dimensions but, to a large extent, highlight a perceived disconnect between treatment and care. They also draw attention to the fluctuating nature

of care and trust; the latter was precarious and conditional on the ability of clients of drug treatment to adhere to specific rules and expectations.

Dehumanising Experiences

The requirement to provide urine samples under supervision was consistently singled out by participants as a source of stress and humiliation, with a large number recounting ways in which the practice engendered feelings of embarrassment and shame. Participants used the terms 'degrading', 'demoralising' and 'mortifying', among others, to describe the experience. Mirrors and the presence and surveillance of another person featured centrally in these accounts.

"You're standing there trying to go to the toilet and there's someone standing behind you and there's a mirror here and a mirror there so they can see everyone and you don't feel comfortable, you know like?" (Tommy, age 40-44)

"The methadone urine system, yeah, sure like you're sitting in the clinic ... They just don't care because, with the attitude with the staff and the clientele, there's no like, it's just, the staff do look down their nose at everyone. And you feel that." (Alvin, age 40-44).

Men in particular described physical and psychological barriers beyond their control to providing urine samples under supervision.

"I can't go (urinate) when someone's watching me, mirrors and all ... Like, I could be bursting, I mean literally bursting to go to the toilet, and I can't go. Then the minute I walk outside I have to nearly run down a lane to go ... and then once I go into the clinic, it's like someone's after chopping off my privates. It's weird like." (Noel, age 35-39)

"I had to piss in a cup every time and I've kidney problems so it wasn't easy. It wasn't easy but I did it." (Seán, age 50-54)

"There is times when you can't perform and you need to go so what can you do? You have to sit there until you give it." (Ronnie, age 45-50)

The requirement to provide samples was also strongly connected to potential sanctions, leading to client resentment because they felt judged 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'. Fuck off, like. People have slip-ups, do you know what I mean, they relapse. 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)

One participant maintained that urinalysis served to reinforce the stereotypical image of the drug user as "junkie".

"It was mortifying. Depends who was supervising as well. Like some are ok and some are just, I don't know? 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 even sort of reinforce that junkie mentality that you need something every day, whether you need it or not." (Lorraine, age 40-44)

Beyond the setting of the clinic participants also reported experiences that led to diminished feelings of self-worth. Several who attended a pharmacy reported positive experiences of both pharmacy staff and the system in place for consuming methadone on-site and/or collecting their takeaways in the pharmacy they attended. At the time of interview, four attended a pharmacy on a daily basis, seven once weekly and three more than once a week; a further two attended less frequently and three had attended a pharmacy in the past. Of these, nine recounted experiences of being treated differently to other customers and seven reported what they depicted as incidences of public humiliation during pharmacy visits. Having to wait while other customers who arrived later are served was commonly said to be an experience that left participants feeling stigmatised.

"You go into the chemist or whatever to get your phy (methadone) and you're left standing in the corner like a leper." (Dillon, age 35-39)

"If there's other people coming in, you're left standing, they literally will not deal with you if they have other customers, which is a bit degrading ... with the chemist I'm with now it's a case of wait until everyone is gone, you know." (Alvin, age 40-44)

Yvonne described her humiliation during a recent pharmacy visit when a locum pharmacist discussed her methadone dose publicly.

"There's stand-in chemists, do you know, pharmacists. And one there (some months ago) your man (pharmacist) shouted down from behind the counter. And I was actually talking to a neighbour at the time, and he goes, 'We haven't got any of these size cups for your methadone so we're going to put it in one of these ones, is that okay?'. And I'm standing next to my neighbour who knew nothing. And I tell you, the ground couldn't open up fast enough. I just wanted to die. And then having to say to me neighbour, 'It's my methadone, I'm sorry, do you know, I'm on methadone'".
(Yvonne, age 40-44)

Some participants were critical of the layout and physical structures in place for the on-site consumption of methadone in the pharmacies they attended, which served to publicly expose them as methadone patients.

"I'll give you a laugh – they put in a partition for us to take our methadone but all the partitions are glass. So everyone can still see what you're doing so what's the point?"
(Catherine, age 40-44)

"At the end of the counter there's a glass door and I just stand in the glass door and drink it and then step back out. So anyone that walks into the chemist wo sees me in there drinking know that I'm drinking methadone because I'm not going to be in there buying medicine and drinking it. And I don't want everyone to know that I'm drinking methadone. I'm not supervised doing wees so I don't know why I have to be supervised drinking it." (Yvonne, age 40-44)

In situations such as these, participants felt powerless. They had little opportunity to conceal their methadone user identity from pharmacy staff or the public and some felt 'outed' to some degree and also demeaned by their visits to the pharmacy.

Lack of Autonomy

Participants in this study appeared to have limited input into the course of their treatment and of particular note was their constrained ability to influence their treatment plan. A large number had entered into MMT with the expectation that they would attempt to 'come off' the substance at some point but learned that this aspiration or goal was strongly discouraged.

"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)

"You're sort of going through the motions, but getting someone off, you'd imagine the treatment services, well in my mind, should be there to get somebody eventually leading a drug free life." (Lorraine, age 40-44)

Yvonne and Conor reported that their attempts to discuss detoxification were largely dismissed.

"I was told, 'Oh no, you don't go off methadone, oh, no, no, no, no, we'll just reduce you a bit'. And then they end up putting you back up again. The doctors don't really want you off methadone." (Yvonne, age 40-44)

"If you say to them (prescribing doctor) that you want to come off it and all, 'Ah, no, I think that would be a bad thing.'" (Cormac, age 35-39).

Participants described many barriers to negotiating specific aspects of their treatment. For example, several told that they had, on numerous occasions, requested a reduction in their daily dose but that the request was strongly discouraged or refused in most cases without a full or detailed discussion of the pros and cons of embarking on such a 'journey'. Others reported feeling sidelined and their wishes dismissed when they requested a dose reduction. Indeed, a majority of participants were critical of what they described as regular offers on the part of their prescribing physicians to have their daily dose increased but with no mention or discussion of a dose reduction.

"Like I see (prescribing physician), I see them once a week or whatever, you know? But all they seem to do is just, 'You alright? Do you want to go up?', you know what I mean, 'Do you want to go up? Do you want to go up?' And you're telling them 'No, I

*don't even want to be on the fucking thing and you're asking me do I want to go up'
Do you know what I mean?" (Conor, age 35-39)*

*"I'm on methadone because I wanna be clean ... so why can't they just trust that I'm
doing it? Say that I'm doing it and let me do it and push for me to do it, instead of
keep saying every week, 'Oh, do you want me to put you up'. Not, 'Why didn't you
sleep?' or 'You didn't sleep because you have a lot on your mind or you're stressed'.
Everything is just, 'Oh, we'll just put you up.'" (Yvonne, age 40-44)*

More broadly, participants sometimes asserted that their knowledge about their personal situations and their bodies was not considered or acknowledged. These respondents felt that assumptions were made about their lives and decision-making capacities.

*"Like the doctor will put me up as high as I want, but when I start questioning, 'Doctor,
can I go down a bit?', it's like, 'Why would you want to go down? What makes you
think that?' You know? It's crazy and the doctors trying to tell you, an addict who
knows his own body, and they're telling you how you feel." (Cormac, age 35-39)*

*"They're giving out maintenance too quick. Maintenance and that's it. It's not asking,
'What do you think?'" (Craig, age 35-39)*

It is important to note that participants who reported a more flexible treatment regime – involving less frequent urine testing and takeaway arrangements – as well as those who attended primary care settings tended to feel more involved in their treatment plan and were less likely to state that their views or concerns were sidelined or dismissed. These participants also tended to be slightly older and to report a greater level of stability in the sense of reporting no or extremely limited drug use, including benzodiazepine use. For example, Jason (age 55+), explained that "I can talk to my doctor about anything" while Kevin had worked with his GP to plan a gradual reduction in his daily dose with the aim of becoming abstinent.

*"We (referring to GP) worked out an idea of how I would eventually come off it
(methadone). And I had that idea but, up to that point, I didn't envisage coming off it
at all." (Kevin, age 55+)*

Conclusion

While all study participants were long-term participants of MMT, they reported quite diverse treatment regimes in terms of their daily dose, the regularity of urine testing, the frequency of their attendance at a clinic, primary care practice and/or pharmacy and their takeaway privileges. Thus, whilst sharing longevity in MMT, their treatment arrangements and, by implication, their positions along a treatment and 'recovery' path differed quite significantly.

In general, participants in this study shared a belief that MMT had improved the quality of their lives, the primary perceived benefit being that methadone had introduced and helped to

maintain a sense of stability and normality. MMT was also reported to have reduced criminal justice contact, enabled the re-establishment of family life and relationships and was also perceived as having health benefits. All of these reported benefits correspond closely with the literature on methadone treatment outcomes both in Ireland and internationally, which has shown MMT to reduce drug-related crime and to improve health and quality of life (Buken et al., 2011; Comiskey et al., 2009; Corsi et al., 2009; Gowing et al., 2008).

Yet methadone occupied an ambivalent place in the lives of most participants. This chapter's exploration of ambivalence particularly draws attention to the perception that methadone was binding rather than emancipating. A number of participants saw their dependence on the methadone prescription on a continuum with their previous heroin use (Notley et al., 2015) while many others questioned the control it exerted over their daily lives (Harris & McElrath, 2012). Participants acknowledged the release that methadone provided from having to source and secure a supply of heroin but, particularly over time, questioned the extent to which the chemical and psychological bind of MMT mirrored their addiction to heroin.

Ambivalence was also undoubtedly related to participants' treatment experiences and, in particular, to the routine of clinic attendance, which had many complex dimensions. Among those who expressed satisfaction with MMT, the experience of being listened to and of having details of their lives heard and responded to featured prominently in accounts of 'good care' (Rance & Treloar, 2014). Echoing the findings of previous research that has examined MMT client perspectives and experiences, takeaway doses were valued by participants for the freedom they offered from the daily routine of clinic attendance and because this privilege or 'reward' was associated with a trusted client status (Fraser et al., 2007; Treloar et al., 2007). However, emerging strongly from the accounts of a large number was a perception that their needs – beyond the immediate and instrumental requirement of a daily dose or 'script' – did not feature in their conversations with health professionals. Furthermore, the limited nature of their interactions with service professionals meant that participants felt sidelined, thus perpetuating a sense of 'us and them' (Rance & Treloar, 2014). Many participants reported feeling humiliated and demeaned when interacting with clinic and pharmacy staff, particularly in contexts where they felt that their privacy and needs were not respected.

Finally and importantly, a majority of participants in this study did not feel that they had any 'say' or control over their treatment regime or in their treatment futures. Methadone maintenance clients' perceived lack of input into treatment decisions has been documented in previous research in an Irish context (Harris & McElrath, 2012; King, 2011; Van Hout & Bingham, 2011). This study's findings adds depth and nuance to that experience, highlighting the centrality of participants' relationships with their prescribing physicians to their perceptions of the ways in which their views and perspectives were valued or, alternatively, undermined. Trust was deeply embedded in these accounts. For those who earned trust, there were gains in terms of perceived progress and self-confidence; the reverse was true for those who struggled to do so, who were likely to view the withholding or withdrawal of trust as an individual failure or punishment.



CHAPTER 6

Social Reintegration and the Management of Stigma

Although the term 'social reintegration' is not used uniformly across countries, it is widely acknowledged as a key aspect of a full and successful recovery from drug dependence (EMCDDA, 2012). Social reintegration, defined as "any social intervention with the aim of integrating former or current problem drug users into the community" (EMCDDA, 2012: 28), is concerned with the position of the individual in wider society. Thus, while engagement in drug treatment is an essential step, the wider context within which treatment unfolds – including education and employment, housing and family relationships – must be considered and addressed (EMCDDA, 2012; Keane, 2007; Neale & Kemp, 2010).

This chapter seeks to extend understanding of the study participants' lives beyond MMT. It starts by discussing employment, which is a critical 'plank' of social reintegration (EMCDDA, 2012; Keane, 2007). The analysis then turns to housing, focusing on the impact of housing stability, housing precariousness and homelessness on participants' lives. Participants' relationships with family members and friends are examined, as well as what many depicted as a lives characterised by social isolation. The chapter concludes by examining stigma, which permeated the narratives of the study's participants, acting as a significant barrier to what is generally understood as 'social reintegration'.

Employment

Just three of the study's 25 participants, all women who worked full-time, were employed at the time of interview. The vast majority had worked in the past, although not for many years in most cases. Those who reported a history of labour market participation had typically worked in low-paid jobs, often on a casual basis, which meant that many did not have a formal employment record. The absence of an employment history, coupled with low levels of educational attainment, created significant barriers to labour market participation. Several articulated an awareness of their highly disadvantaged position when seeking employment because of their lack of formal educational qualifications.

"... you need like, you need certificates just to work in McDonald's now. Like that's how bad the job situation is that even they can say like, 'Ah well, you need your Junior Cert or whatever. I left school well before that, I don't have a CV or anything like.'" (Richie, age 40-44)

"I don't have any education and they say even your Junior Cert won't get you a job now, you need a Leaving Cert." (Craig, age 35-39).

A range of additional barriers to seeking and gaining employment were discussed by respondents. Among these, the problem of having a criminal record was a frequently noted challenge with 13 of the study's male participants stating that their prior criminal record presented what seemed, to at least a number, like an insurmountable obstacle in seeking employment.

"I sent CVs out and all but most of them are looking for this Garda vetting. And then once the Guards say, 'Yeah, he's been in trouble' ... but it's been seven or eight years ago, I think it could be longer now but I'm not really sure at the moment. But that wouldn't look good." (Tommy, age 40-44)

"Well when you're filling in forms, CVs and that, they do ask questions like criminal records. It was like, should I? I did have some, they weren't burglaries or robberies or things like that, they were just like, stupid things, really." (Danny, age 40-44)

The demands associated with a daily routine of MMT – in terms of maintaining clinic and/or pharmacy appointments – were highlighted by others as hampering their ability to maintain a job if, indeed, they managed to secure employment in the first instance. Craig, who previously held what he described as 'cash-in-hand' jobs, told that he struggled to manage clinic attendance during one period when he worked in construction.

"I was working on the building site and it wasn't easy cause I had to go down and give a urine. That was when I was on (the clinic) twice a week – on a Monday and on a Friday I had to go down and during the mornings ... I used to tell (boss) that I'd only be two minutes and I'd be coming back ten or fifteen minutes late so it can be hard that way if you're on a job and you're coming back late all the time. People start to get suspicious, 'What's going on like, you only live over there like?'" (Craig, age 35-39)

Other participants similarly spoke about the challenge of potentially having to balance the demands of MMT with those of maintaining a regular job.

"If you're on methadone you need to take time off to get your script, to go to your chemist, you know, and these cause terrible issues." (Catherine, age 40-44)

The daily routine of MMT was one of a number of issues discussed by study participants but, perhaps significantly, was by no means perceived as the greatest barrier to employment. Participants were in fact more likely to express concern about the views of prospective employers should they become aware of their drug use history or participation in MMT. Bernie felt that it would be extremely difficult, but essential, to conceal her 'status' as a drug user in treatment from prospective employers.

"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, d'you know what I mean ... And then you're thinking like, 'What if they ask for a medical?' Even though they don't know me, there is stigma

straight away, like who wants to employ someone who is on methadone?" (Bernie, age 40-44)

One participant, who was employed full-time for a considerable period of time, went to great lengths to conceal her MMT from her employer believing that such knowledge would seriously compromise her position and possibly lead to the termination of her employment⁹. This account illustrates the pressures associated with managing and concealing a biographical past that could potentially be 'judged' and, ultimately, punished.

"This is my, it's like how the icing now on the cake would be, do you know what I mean? I can't believe I'm in such a good job and, again, it's just, you put on your mask and you go out the door (after work). And it's like you present to people and they don't know any different, so therefore they can't judge me, you know?"

Fears such as those articulated by this participant had in fact materialised for a small number. Catherine is one of two respondents who reported losing a job following information received by their employers about their attendance at a methadone clinic.

"I didn't want to tell them (employer) about it (MMT), I didn't want to jinx it. I was working away there for months ... I was so happy in that job. I absolutely loved it ... I was called into the office and sat down and it was eh, 'Well Catherine, it's been brought to our attention that, em, you are in a methadone clinic and we are quite concerned about the parents finding out about this so, I'm very, very sorry but we'll have to terminate you.'" (Catherine, age 40-44)

Caring responsibilities, beyond those associated with their children, were noted by other participants as a barrier to seeking employment. Both Seán and Lorraine were caring for a parent who had significant health problems requiring constant or daily care.

"My mother's very ill at the moment, you know ... So that role will end soon enough and then I'll go onto something else." (Seán, age 50-54)

"I sort of always have worked here and there. Well over the years now like, I haven't spent my whole adult life on the dole because I actually like to work. A lot of my time at the moment, like I said, is tied up with Dad, but I'm so physically burnt out that I don't know if I could hold down a job now." (Lorraine, age 40-44)

Several expressed a desire to have a job, believing that employment would help to bring greater structure and a sense of purpose to their lives.

"I want to be able to go out into the world and further myself like and get work and get, like there is people that can, that are doing it like." (Dillon, age 35-39)

"I'd love to have a job, I'd love to be able to get up in the mornings and have a job and have a wage and whatever and do all the normal things and you know ..." (Seán, age 50-54)

9) As a further measure to protect this participant's anonymity, we have not attached a pseudonym or age range to this narrative excerpt.

However, there were other participants who did not see any realistic prospect of finding a job, with some expressing a sense of resignation to unemployment. At the time of interview, a large number stated that they were not currently seeking employment.

"I don't know? It's been so long since I've done it (looked for employment) that I don't know what to expect really, you know what I mean ... Yeah, I haven't even thought about getting a proper job for quite a while to be honest." (Eric, age 35-39)

Those who were enrolled in CE schemes (five in total) at the time of interview tended to be more optimistic about their future employment prospects. These accounts suggest that participation in employment schemes led to positive engagement with others, helped to counter boredom, enabled planning for the future and also engendered a sense of personal purpose and achievement.

"You come in whatever days and also you can move up in stages and then, at the end of it all, by the end of it all they hope to have you back in society working and drug free altogether like, you know. So that's what I'm aiming for ... so it's good." (Dillon, age 35-39)

Richie, who had started a CE Scheme approximately six months prior to interview, talked of feeling "more deserving" of social welfare payments and having a greater sense of independence.

"... I hated going up and collecting my dole but, since I've started here, it makes me feel like I've earned my money because I'm coming here every day and it makes me feel like a bit more worthy of getting my dole ... because I've come here every day and it's not work, it's a course like, but it just makes me feel better about collecting it and I feel like more independent and things like that." (Richie, age 40-44)

Overall, participants in this study confronted multiple barriers to labour market participation owing to their disrupted schooling, low levels of educational attainment and the lack of a recent employment history. Most who had worked in the past had been employed in low-paid, casual work, often in the construction or service sectors and, consequently, did not have a demonstrable employment history. Other significant perceived barriers to employment included employer perspectives on the drug user or 'addict' and a belief that prospective employers would not consider hiring a person with a history of drug use.

Housing

As documented in Chapter 3, the housing situations of study participants at the time of interview varied. While almost half (n=12) were independently housed – living in local authority (n=7) or approved body housing (n=2), in the private rented sector (n=2) or a privately owned home (n=1) – seven currently lived in transitional homeless accommodation. A further five participants, all male ranging in age from their late-30s to early-50s, lived in the home of a family member. Some participants who lived with a family member(s) felt that their

housing was secure but others were vulnerable to the loss of housing. For example, Alvin, who had a history of homelessness, currently lived with two family members and slept on a sofa in the living area of the residence. Explaining that "I never really had a stable place to live, I've been on and off homeless since I was about 16", he considered his living situation to be very unstable.

[So how do you feel about where you are living?]

"It could be better. It's not a good place to live. They've (family members) let the house fall into disrepair big time. It gets you down waking up there every morning looking around and living in that environment. It reminds you of being back on the streets and all the rest, you know." (Alvin, age 40-44)

Alvin had approached his local authority in an attempt to find alternative and more secure housing but was informed that his application would not be considered until he was "clean".

"I've been in touch with the local authority and they did offer me a place about two years ago but I went for the interview and it didn't go well. They put it on hold, literally, 'Until you get your act together, basically get clean and get stabilised' and come back and see them then ... I have to get clean and, like I said, the council won't entertain me until I get clean." (Alvin, age 40-44)

Another participant, who had experienced homelessness in the past and currently lived in the family home, worried about the sustainability of this housing: "If anything happens with my father now I'm homeless like, you know" (Cormac, age 35-39). The experience of living in situations of 'hidden' homelessness, either currently or in the past, was reported by a considerable number. At the time of interview, Dillon was moving between the homes of relatives and, at times, stayed in the home of his partner's family. Following his release from prison a number of months previously, he had initially stayed in homeless hostels.

"When I first got out of prison I was homeless, there was nothing in place for me ... And they had me in a hostel in town there and it's just them hostels in town. Like they're just, you have to be sleeping with one eye open, behind the curtains and all, it's just not, so I'd rather sleep rough." (Dillon, age 35-39)

Therefore, although not currently accessing homelessness services, a number of participants were precariously housed and felt uncertain about their housing futures. Those who were currently living in transitional homeless accommodation frequently expressed anxiety about their situations. Six of the seven participants who were homeless were male, almost all of them in their 40s.

"At the moment things are not very good. Homeless, still on drugs, struggling with that and ... you could say the best present that could happen to me is to sort out the accommodation, my addictions, that would be my dream. But I know it's not going to happen overnight, I know it's going to take time." (Danny, 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. A considerable number of others were vulnerably housed and at risk of homelessness while seven were currently accessing homelessness services. There are some noteworthy gender differences in the housing situations of study participants, with women more likely to live in local authority or approved body housing and men more likely to live in the home of a family member or to be currently accessing homeless accommodation.

Social Ties and Relationships

Social ties and the presence of supportive others in people's lives – including family members, peers and community members – are considered to be important to the reintegration of people who have substance use dependency problems (Brown et al., 2004). Furthermore, effective drug treatment may be significantly influenced by the quality of an individual's interpersonal relationships (Broome et al., 2002). This section presents participants' accounts of their family and peer relationships. It also examines accounts that were strongly suggestive of self-isolating practices or responses, sometimes used by study participants as a self-protective strategy but also closely connected to feelings of exclusion and marginality.

Family Relationships

Accounts of the nature and quality of family relationship varied. Ten participants (including seven males and three females) stated that they had family connections that provided some level of support; a further 10 reported strained family relationships while five participants had no contact with family members. Six of the seven participants who currently lived in transitional homeless accommodation reported that they had either a strained relationship with family and limited family support (n=4) or no family contact (n=2).

When family relationships were present, participants reported meeting and sharing 'news' and everyday experiences. Chris lived in the family home and described family as "very important". His sister had always supported him and he also had a good relationship with his brothers.

"Yeah, they (family) do support me, yeah. My sister is very supportive. She always did support me in the past. I mean everyone has their own life but she always took time out to try and help me if I got into trouble or anything like that ... But, yeah, I'm happy with the way life is with my family, you know." (Chris, age 35-39).

Also resident in the family home, Eric was grateful that his parents had not asked him to leave many years previously. He explained that he was trying to make amends for the trauma suffered by his parents because of his drug use, recognising that others with a history of drug dependence could not count on the support of family members.

"It's harder for other people, I have my family around me, some people don't have that so it's harder for them. There's no one to like give them a boost or whatever, you know what I mean." (Eric, age 35-39)

Ronnie, who said that his relationship with his siblings was "healthy now at the moment since I've been clean", also openly discussed the impact of his drug use on family life.

"So the whole family had to turn their back on me and there was a lot of discord that I brought to that family. You know, when you're an addict, especially when you're a heroin addict, you don't realise, you think that you're only hurting yourself, but you don't realise the whole family behind you and the disruption you cause. The heartache you cause people who are worried about you and this, that and the other."

(Ronnie, age 45-49)

Over time, some participants had succeeded in resolving past tensions and their family relationships had improved, sometimes quite dramatically. A number of others reported a more gradual process of renewing family relationships.

[And do you feel like, at the moment, you have support from family?]

"I suppose you can never have enough support but, like, it's getting better, yeah, it's improving for me like." (Dillon, age 35-39)

"I'm getting, in the last couple of months now I (pause) see my mother and father are still living down in (provincial town), you know? But I'm, I'm starting to get back to like, back talking to them and all, you know? And like I get on well with them."

[And were things difficult for a time with them?]

Yeah, they were, they were like on account of like that I was fucking using heroin, you know." (Conor, age 35-39)

However, a large number described their family relationships as fragile, strained or even fraught. These participants sometimes had contact with one family member (a parent or sibling) but not with others. Lorraine explained.

"I'm very grateful to my family that they still consider me or allow me to be a member of or part of the family, you know what I mean? Because I put them all through hell I suppose, you know. They had to watch me turning from a normal sort of sister into this. There was obviously a lot of stealing going on over the years, you know, 20 quid here, 50 pound there and stuff and I'm ashamed of my life of that. Like we still meet up at ... and it's civil and, you know, it's fine, but there's no, apart from (sister) now, I'm not really close with the rest of them." (Lorraine, age 40-44)

Like Lorraine, many others talked about the feelings of shame they harboured over the family ruptures associated with their drug use and to related behaviours such as stealing and lying which very often resulted in their estrangement from family for many years. Ongoing tensions meant that, while some had re-established contact with a family member(s), these relationships were sometimes superficial and lacked meaning. Christine, who said that there had been "no acceptance for who I was or what I was" from her family, maintained contact with her sisters but they met only occasionally and their interactions tended not to progress beyond the exchange of pleasantries.

"I've three sisters, but I wouldn't have any relationship. I mean I do talk to them, I say, 'Hello, how are you? How's things?' I wouldn't visit them, they wouldn't visit me. But when I see them I'm polite to them and they are to me and they say 'How are you?', 'How's the kids? Great, that's it.'" (Christine, age 50-54)

Catherine, another participant who reported strained family connections, explained that she does not disclose the truth about her methadone consumption to family members because of a fear of being judged or rejected.

"I tried – my family – my Mam now she still asks me the same question every time I see her, 'Are you still taking that methadone? Are you not off that stuff yet?'. As far as she can tell I've been on it forever. So I don't tell them how much I'm on ... If they ask I won't, I certainly won't tell them I'm on 85 mls because they've known me to be down to 25, you know?" (Catherine, age 40-44)

Those participants who had limited or no contact with family members often expressed a mix of hurt and anger about how they were perceived, despite their efforts to make changes in their lives. Leanne's parents were deceased and she had very limited contact with her siblings.

[Do you have contact with your siblings?]

"No, not really. No because you can't bring the person with you. There's just ... because of shit that I done when I was much, much younger, they think I'm still like that. I remember going to (a relative's) wedding a couple of years ago and them coming over and thanking me at the end of the night for behaving myself and looking well. I felt disgraceful, I felt disgusted." (Leanne, age 40-44)

Only a minority of participants described constant supportive relationships with key family members who were aware of their drug use history and with whom they felt able to share or disclose the details of their current drug treatment situations. Family members were not available to a large number or in a position to provide social, emotional or financial support. Difficult relationships with family members were a significant source of stress, compounded for some by a belief that they were ultimately to blame for these family ruptures.

Peer Relationships

Relatively few participants reported that they had 'good' friends with whom they interacted or socialised on a regular basis, with just three describing an active and varied social life. Rachel had completed several courses where she met new people and, more recently, had travelled abroad on a number of occasions. She was connected to a peer network and had friends who were available for social outings.

"I go out with friends, like we just go out really for dinner or tea or a walk on the pier or something like that. I don't really go out socialising, as in partying, I'm not like that but ... like, it was my birthday there last week and a few of the girls came along, eight or nine of us and we all socialise and have dinner and a great laugh." (Rachel, age 40-44).

Seán, who described a "pretty simple" daily routine, also discussed his involvement in a number of social activities.

"I just live a pretty simple life, I walk the dog, I do a bit of fishing ... I'm part of a fishing club where we travel up and down the country. You know, completely different

lifestyle to the chaos that I came from, absolutely completely. I'm quite contented and happy, reasonably, you know." (Seán, age 50-54)

The vast majority, however, described limited engagement with social activities or peers, with many reporting that their social circles were extremely limited or non-existent. These participants had few, if any, dependable or trusted people in their lives.

"No, I don't have friends. The only social thing I do is go to the gym twice a week. I don't go out at the weekends, I don't go out drinking, I don't meet people for dinner. I mean, if someone says to me, 'Do you want to meet for dinner?', I'll meet for dinner, but I don't have (pause) ... I couldn't say to you, 'Oh Mary's my friend', because I don't have a Mary, you know." (Christine, age 50-54)

"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)

Past peer relationships were invariably depicted by participants as not equating with 'real' friendships, with very many describing their former drug-using friends as "associates" or "acquaintances".

"You see most, as I said, most of the people I'd link in with I'd only call associates because I'd only know them through drug use." (Dillon, age 35-39)

"I actually hadn't really no friends, I had acquaintances." (Seán, age 50-54)

Simultaneously, many talked about running into 'old' friends, either in the street or when attending the clinic. Irrespective of participants' level of contact or engagement with former drug-using peers, all were clear that they needed to cut ties with these networks and with the social 'scenes' and connections that had previously occupied a prominent place in their lives.

"Yeah, I just don't do anything. I kind of keep away from the old associates like, you know, because I don't want to be getting brought back into that scene as such, you know. I just kind of stick to myself type of thing, just staying away from people that I know are using ..." (Dillon, age 35-39)

"I don't hang around that area anymore because bumping into old faces leads to bad things, you know." (Chris, age 35-39)

A number of these participants also told that they had experienced rejection by friends who learned of their heroin use many years previously. This meant that revisiting relationships with past friends beyond those associated with their network of drug-using peers was not an option for most.

"Friends that, like they heard I was doing heroin and didn't want to talk to me anymore, stuff like that, you know. But as far as I'm concerned, go on, go away, call

me what you want. I am who I am." (Chris, age 35-39)

"I still have friends from when I was growing up before I started taking drugs or when I just started smoking hash. But like when I was in addiction, they kind of stepped back from me to protect their family and themselves." (Richie, age 40-44)

Particularly in more recent years, many had experienced the loss of friendships with very many recalling the death of close friends, which were almost always said to be drug-related. Participants often discussed feelings of sadness associated with this loss and several also articulated an awareness and fear of the association between dependent drug use and early and accelerated experiences of loss and death.

"So many people are dropping dead in the last eight years. I've buried more friends than (pause)... I can't even count them and it's terrifying. All the old school addicts are all gone." (Catherine, age 40-44)

"I've seen so many of my friends dying with their livers and hep C." (Cormac, age 35-39)

"Most of my friends have passed away now ... people start dying after 45, that is a hard fact. Not many live, who are on methadone all their lives, after they hit 50." (Yvonne, age 40-44)

For a majority of participants, friendships and the notion of having friends presented significant challenges and, to some extent, tested their ability to cope with opposing and sometimes contradictory personal narratives and experiences. Some had experienced rejection as teenagers or young adults by their more conforming or law-abiding friends who opted to distance themselves from them for various reasons. Simultaneously, practically all participants felt a need to detach and dissociate from individuals who belonged to their former circle of drug-using peers. Particularly in more recent years, most had experienced bereavement associated with the death of friends, leading to sadness and feelings of anxiety and stress. Thus, friendship was a complicated 'space' for many, its meaning closely connected to prior drug use contexts, connections and interactions as well as to the loss of one or more of these friends. Forming new relationships and friendships was often perceived as daunting, leading many to withdraw from social relationships.

Self-Isolation

A large number of the study's respondents avoided social contact, often describing very little interaction with others on a daily or weekly basis. This self-isolating behaviour appeared to be an 'abstention' strategy for some, who feared that mixing with others with whom they used drugs in the past could result in a return to the social circles that were part and parcel of their (problematic) drug use histories. Dillon, who described himself as "kind of isolated", discussed not "getting out" and "finding new things".

"I'm not really doing anything active or I'm not getting out, I'm not changing, I'm not finding new things to do. I'm still kind of isolated away, like I'm not finding hobbies or anything, you know ... Yeah, I just don't do anything." (Dillon, age 35-39)

Alvin similarly reported that he spent a lot of time “hiding away”, explaining that he found it “pretty hard to reintegrate into normal society”. He had few social connections that he felt were positive or productive and, for that reason, tended to self-isolate.

“I would go fishing during the summer, I do a bit of fishing ... Other than that I sort of isolate myself a bit, I'm not one for hanging around on the streets. The way I look at it I've done enough of that over the years, you know. So other than that and visiting the brother at the weekends I wouldn't really be out and about much.” (Alvin, age 40-44)

Feelings of guilt and shame related to past drug use and associated behaviours appeared to negatively impact some participants' ability to have or form new relationships because they feared judgement or rejection by others. These participants expressed ways in which their life and drug use histories hampered their abilities to foster and maintain relationships.

“And, you know, I've to live with the guilt of things I've done. I've to live with (pause), I've hurt people, I've hurt my family, I've hurt myself, you know? I let my mother down and every negative aspect that comes with drug addiction, I've gone through, you know?” (Cormac, age 35-39)

Isolation overlapped with loneliness in many accounts, particularly among those who lived alone or in homeless accommodation.

“Like I've met a girl now and, you know, I'm trying ... But I've been going home and the loneliness of it all.” (Cormac, age 35-39)

“I'm probably quite lonely. It doesn't get me down too much but it's a fact. I can take it because I've been an outsider all my life anyway but I would say other people being this lonely would probably (pause) ... it would become a problem for them.” (Kevin, age 55+)

Accounts of seclusion and loneliness were also articulated by participants who were securely or independently housed. Yvonne, who had recently moved to local authority housing, worried about whether her own isolation negatively impacted her children's ability to socialise with their peers.

“You see, because I don't mix with people I find they (children) don't mix with people. Nobody ever calls to my house, no one ever knocks on my door, I never get a phone call saying, ‘Do you wanna come here or do you wanna go there?’. So they (children) just see me just on my own constantly ... So I find they don't mix with people either, you know. I'd even say to (son), ‘Tell your friends to call up’ and ‘No, no, no, it's grand, it's grand, it's grand’. So (pause) ... but they kind of need a bit of help socialising.”
(Yvonne, age 40-44)

For a number, growing older as a long-term MMT client amplified feelings of marginality, making social interaction more difficult. In Catherine's case, these challenges were compounded by poor mental health.

“I find the older I get the more different I feel and the harder (pause) ... I'm finding it

really hard to mix with people who don't use and I was never like that before. And now, it's really starting to get to me now. I don't know if that's because I'm going through a really bad patch of depression at the moment." (Catherine, age 40-44)

A number of female participants talked about the absence of an intimate relationship in their lives. The women quoted below had been involved in violent relationships many years previously and had not subsequently formed new romantic ties. They now had older or adult children, which meant that their caring responsibilities were no longer as time-consuming or demanding. Both talked openly about a desire for intimacy, closeness and companionship in their lives.

"I've sort of been on my own for so long now, you sort of get used to it and it sort of suited me in the beginning ... when I got away from him (former partner) I sort of didn't want anyone else. I used to get a lot of offers whereas now (laughingly), I'm not going to get any. I'd say I'm going to be left on the shelf. But, yeah, that sort of loneliness is physically painful, as well emotionally, but I just can't see that ever changing." (Lorraine, age 40-44)

"I don't have friends and I've never had a partner since the day I split with my kid's Dad and I think that just kept me safe. I didn't want another man coming in and maybe hitting me in front of the kids or something like that or demanding the kids or ... I just didn't bother. And now I'm (older) and I'm kind of going, 'God, I wouldn't mind, I wouldn't mind someone with me to go away with.'" (Christine, age 50-54)

Another female participant felt that she would not be accepted as a romantic partner because of her status as a methadone patient.

"To have to actually tell them (romantic interest) one day that you're on methadone. They'd run a mile – they wouldn't want to bring you home to mammy and daddy. Do you know what I mean, so you kinda, I'm cutting meself off from that side of society because of this fuckin' thing (methadone)." (Catherine, age 40-44)

For a large number, operating in the conventional world of family, peers, neighbourhood and social life presented significant challenges. Already marginalised by their lengthy drug use histories – and the losses associated with a drug user 'identity' – a majority were relatively socially isolated. Participants demonstrated an awareness of the obstacles created by social isolation but, equally, seclusion and a fear of interacting with others was a significant dimension of life experience that many found difficult to confront and address.

Managing Stigma: "I'm always hiding and ducking and diving"

"Well, you know, if people know you're on methadone, they do treat you completely different. You know, they do, they don't take you seriously like. I find when people don't know anything about that, they actually treat me like just a normal person ... If someone seen me coming in here (the clinic), they might tell my (adult child), they might tell one of my family or something like that. So I'm always hiding and ducking and diving and waiting on all the cars to pass, you know? I've often missed the clinic from hiding down the road." (Christine, age 50-54)

Despite its efficacy and widespread use, MMT continues to be largely stigmatised and stigmatising, with patients often experiencing stigma and discrimination associated with their treatment (Conner & Rosen, 2008; Lloyd, 2013; Woo et al., 2017). Indeed, the stigma associated with MMT is said to be particularly strong (Earnshaw et al., 2013; Smith, 2010; Tempalski et al., 2007). Institutional stigma – which denotes those negative attitudes and beliefs towards methadone reflected in an organisation's policies, practices or cultures – has been documented in the literature (Anstice et al., 2009; Harris & McElrath, 2012). Other sources of stigma experienced by MMT clients include the family, friends and the neighbourhood (Earnshaw et al., 2013; Conner & Rosen, 2008). Finally, self-stigma, which refers to “negative thoughts and feelings (e.g. shame, negative self-evaluative thoughts, fear) that emerge from identification with a stigmatized group” (Luoma et al., 2007: 1332) is an important, albeit lesser explored, dimension of stigma. Self-stigma occurs when people internalise public attitudes and can lead individuals to suffer negative consequences, including decreases in self-esteem and self-efficacy (Corrigan & Rao, 2012).

Accounts of stigmatising experiences were pervasive, with participants frequently confronting stigma on multiple levels as part of everyday life. This section examines the ways in which stigma was experienced by study participants, with particular attention directed to the stigma of MMT.

As documented in the previous chapter, participants frequently described ways in which they felt stereotyped as methadone treatment clients by medical and other professionals in the clinics they attended. For example, many recounted feeling stereotyped as not trustworthy and incapable of decision-making in relation to their treatment. Negative experiences of interacting with clinic and pharmacy staff were highlighted, often with reference to what participants felt were responses based on stereotypical assumptions about their lives. Institutionalised stigma of this nature extended beyond drug treatment settings and included several other contexts where participants reported experiences of being 'singled out', treated differently, excluded or demeaned because they were clients of MMT. Maternity hospitals were specifically mentioned by four of the study's women as places where they felt exposed, humiliated and publicly ostracised.

“Well my hospital chart, straight across the front, it said ‘methadone’, where everybody else in the hospital could see. All the other normal people and I’d be sitting in the place with methadone right across my file. And then every time I went in I was treated like I was just a dirty, dirty, drug addict who was just, ‘I don’t even wanna touch her. Just get her done, get her out, she can’t be clean’. They would not believe me that I was clean.” (Yvonne, age 40-44)

Rachel, who reflected on her hospital visits during pregnancy many years earlier, told that it was only in hindsight that she understood the impact of how she was treated.

“So it was only in hindsight that, like after the fact, and all the years later that I look back and go, ‘Jesus, such a terrible way to treat someone’, you know what I mean like. But when you’re in it, you’re on the floor like with it, you don’t really see that it’s so, so damaging to be treated so badly.” (Rachel, age 40-44)

Several others recounted negative experiences of interacting with state agencies, including housing, homelessness and social work services. These accounts tended to emphasise a constant preoccupation on the part of the individuals with whom they interacted with their drug user or 'addict' status: "When I went to the council, all they were focusing on was the heroin, the drug use, you know ... they just looked down on you straight away and they just think you're what they would see on the streets" (Alvin, age 40-44). In situations such as these, participants did not feel that they could 'speak back' or challenge the assumptions that were made about their lives. These experiences were reported to have traumatising effects, one of the most significant being a belief that it was impossible to escape, much less resist, these structurally reinforced stereotypes: "I got an identity to that now. Maybe, yeah, it's negative thinking but it is the reality of what's after happening in my life" (Cormac, age 35-39).

Stigma experiences were not limited to institutional contexts. Indeed, several respondents talked more frequently about everyday stigmatising encounters in their neighbourhoods and also in their interactions with family members. Yvonne told of the response of parents in her neighbourhood who became aware that she was a methadone client and would no longer engage with her in the school yard. She expressed strong concern that her children would be treated differently as a consequence.

"Well yeah, some of the parents saw me going into the methadone clinic and they haven't spoken to me since ... And these would be parents of kids that would be in the same class as me kids. But they seen me going into the clinic and then they're like, 'Oh, she's a druggie'. And then you're looked at totally differently. And some parents at the school they still don't talk to me because they seen me going into the clinic two years ago ... Because I'm going in the clinic I'm obviously a junkie so avoid her. But then you feel that, 'Oh, me kids are going to feel differently' because they're probably saying to their kids, 'Don't hang around with that kid'. And it ends up passing down and going to the kids because I was seen going into the clinic." (Yvonne, age 40-44)

Accounts of stigmatising experiences in the neighbourhood were sometimes strongly connected to clinic and pharmacy attendance. The public nature of these settings meant that participants were observed by others in the community, making it difficult to conceal their status as methadone maintenance clients. Some felt publicly exposed and shamed by this experience.

"Sometimes you feel that people know you're on it (methadone), you know, and they look at you, they look down on you. I used to get that a lot, especially being I have to drink the methadone in the chemist even though you go in behind the thing (partition). But I do find if you're drinking it there that people will be looking at you." (Ciara, age 40-44)

"Like when I'm going into the clinic and you have to turn around and show your face and people see me going in and (they're thinking), 'I thought you stopped that (methadone) years ago.'" (Deirdre, age 35-39)

Like Deirdre, others made reference to their age and the longevity of their treatment, both of which constituted additional layers of stigma and shame.

"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)

Beyond public settings, participants also recounted stigmatising experiences arising from their interactions – or, more commonly, their lack of interaction – with family members. As documented earlier in this chapter, the quality of participants' family relationships varied, although many reported ongoing family tensions as well as distant or fraught relationships with one or more family member. Referring to the assumptions made by some family members, a number felt that they had lost the trust of family. Bernie was not invited to family gatherings.

"I wouldn't get invited to family things like. I think they thought I was a robber or something because I was on drugs. Do you know that I never robbed anybody while I was on drugs." (Bernie, age 40-44)

Exclusion from family events was reported by others and was often depicted as particularly hurtful. Others responded with anger: "I didn't get invited to (family) christening. I don't get invited to family do's (gatherings) so to hell with them" (Leanne, age 40-44).

Participants in this study were managing the impact of stigma on a constant basis, with many expressing hurt, upset and distress about how they were perceived by others. However, for most, the impact of stigma was a deeply private experience. Referring to the prejudice that surrounds addiction, Alvin explained his attempts to "fight back".

"There's a lot of prejudice to drug addiction, you know. They're all, 'Oh it's their own fault'. But, you know, when you try and battle back, the resistance, the resistances are phenomenal ... you've to fight and claw for your life." (Alvin, age 35-39)

Later in the interview, Alvin elaborated on the effects of stigma, commenting that developing a "thick skin" was perhaps one inevitable consequence. For Alvin, 'accepting' the responses of others was an option but not one that would negate the lived experience of stigma.

"It's just the stigma sometimes, you know, that I have to fight all the time, you know? Like growing that thick skin, because people aren't just going to accept you for it. Ah yeah, people say, 'Well done, you're doing great and fair play', and all, but there's other people, 'Ah you're a junkie scumbag'. And all this goes on ... People say hello to you in the street and shake your hand, 'Fucking see him? Sweet Jesus, he's on methadone'. But that's part of life and, you know, if I was to say, 'Yeah, I do accept it', it doesn't mean it doesn't hurt anymore." (Alvin, age 35-39).

Alvin's account illustrates the multiple layers of stigma that were "part of life" for a large number. Irrespective of gender, stigma was internalised by participants: "That's what you do as a drug addict – you let people down, you're unreliable, you're of fucking no use to nobody" (Cormac, age 35-39). However, narratives of self-stigma were particularly apparent

in the accounts of female participants and also had some distinctive characteristics. For example, a number referred or alluded to change in their bodies and physical appearance and several talked about dental problems and tooth loss, which they found distressing. Lorraine felt that she was “judged” because of her appearance.

“My appearance has changed a lot in the last sort of 20 years. I didn't look like this, I used to be pretty. I suppose I've lost all my teeth as well. Well, I look like a junkie now and people judge, I certainly get judged a lot on my appearance.” (Lorraine, age 40-44)

Self-critical remarks featured strongly in the accounts of some of the study's women, particularly when they reflected on their situations, past and present, and their 'journeys' through drug treatment. When asked what methadone meant in her life, Christine responded by suggesting that the substance mirrored the “worst” part of her.

“It's always, it's (methadone) like holding up a mirror and saying, 'This is the worst of you,' you know. I can't function properly. I want to do so much in my life but it holds me, it holds me back for me. It's a bit like a jailer really, isn't it?” (Christine, age 50-54)

Speaking about the negative consequences of a relapse during her 30s, Catherine harboured strong feelings of regret, recalling that she could have made better choices during what was a particularly challenging period of her life. She questioned whether she could, in the future, embrace the “good stuff”, describing herself as a “junkie in disguise”.

“You know, I've had so many opportunities like come my way and I'm not able. I don't feel (pause) ... I feel like I'm a fake, that I'm a fraud ... that if I try to go and do all this good stuff that I'm a junkie in disguise.” (Catherine, age 40-44)

Stigma, which is linked to institutional, public, and private shame (Vigilant, 2004), was very present in participants' accounts of everyday life. Managing the stigma of drug use and drug treatment – often depicted as a deeply private experience – presented numerous challenges connected to feelings of rejection, hurt and anger. Irrespective of participants' responses, stigma acted as a strong barrier to social participation and also thwarted the self-improvement aspirations and efforts of a large number.

Conclusion

As stated at the outset of this chapter, social reintegration – which encompasses “activities that aim to develop human, social, economic and institutional capital” (EMCDDA, 2012: 14) – is considered to be a foundation for drug treatment and recovery from drug dependence. The findings presented in this chapter – which have focused on participants' everyday lives, experiences and relationships – strongly suggest that the vast majority were not socially integrated and that this lack of integration placed them at high risk of further social exclusion. Most were unemployed, several were homeless or precariously housed and a

large number did not have access to social support from family members or friends. In other words, participants in this study had multiple unmet needs in relation to housing, education, training and employment.

Prominent in the accounts was the extent to which participants engaged in self-isolating practices. Other studies have similarly found older drug users to self-isolate because of embarrassment, shame and/or a fear of rejection by family members and others in the community (Ayers et al., 2012; Smith & Rosen, 2009). A large number described daily lives characterised by seclusion and loneliness, often related to a lack or absence of social relationships but also strongly associated with stigma, which most experienced on multiple levels. Drug addiction stigma continues to impact the lives of individuals with a history of problematic drug use, even after they access treatment (Earnshaw et al., 2013) and there can be a particular stigma attached to MMT (Lloyd, 2013; Woo et al., 2017). The findings presented in this chapter indicate that growing older as a long-term methadone patient exacerbated feelings of stigma and stigma-related stress. A powerful, yet frequently unspoken and silenced experience, addiction and drug treatment stigma undermined participants' ability to participate and experience a sense of belonging in their communities. Furthermore, the range of institutions with which they interacted – including those related to drug treatment, housing and health – frequently served to legitimate discourses that reinforce and uphold the stigma of drug use, addiction and methadone treatment.



CHAPTER 7

Methadone, Health and the Meaning of 'Recovery'

Individuals who are older and/or long-term participants in methadone maintenance treatment programmes can suffer a range of physical and mental health problems (Doukas, 2011, 2017; EMCDDA, 2010; Rosen et al., 2008). Understanding the self-reported nature of physical and/or mental health problems – and how MMT clients frame and understand health-related difficulties and challenges – is important since these conditions may significantly impact quality of life as well as individuals' ability to fulfil desired goals and to reintegrate and recover. This chapter examines study participants' health, with particular attention directed to how they described the impact of physical and mental health on their everyday lives. Reported levels of engagement with health and social care services are discussed and the chapter concludes by examining the meanings that participants attached to the notion of 'recovery'.

Physical Health

Participants in the study reported a host of physical health problems, including both chronic and acute illnesses and a range of everyday 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 reported chronic illnesses included respiratory, renal and coronary diseases (n=9).

Fifteen participants (60%) had tested positive for hepatitis C. Of these, five had received treatment and described themselves as 'cured' or disease-free. A further five were not receiving treatment, while two were being treated for hepatitis C at the time of interview. Three participants stated that while they had been diagnosed with hepatitis C, it was either dormant or had self-resolved. A majority who reported a diagnosis of hepatitis C stated that they had most likely contracted the disease through the sharing of needles or other drug use paraphernalia in the past. While most reported that they had been generally vigilant about avoiding needle sharing and ensuring that they had access to clean drug use paraphernalia, this was not always possible, as Ronnie explained.

"That's not to say that, you know, there has been a couple of times where I have shared needles. Now I'd often throw it in a kettle of boiling water after somebody

and using it, but there has been times when I'd have to dive into a bush, you know, or into a doorway. Then in prison, you know, in prison like you're, especially if you're on remand, that needle is going around twenty to thirty people." (Ronnie, age 45-49)

Participants who had completed the treatment for hepatitis C frequently expressed relief, a renewed sense of health and ability to re-engage.

"I think once that was gone out of my head that I had hep C, I then started (pause) because I felt healthier in my body and mind so I've now started the gym and things like that." (Christine, age 50-54)

"I'm finished up (treatment) on that the end of this week and my viral count is down to zero. The virus is gone completely. Delighted with that because I've carried that for, oh, over 20 years, I think. And fatigue was a huge factor with the hepatitis C." (Ronnie, 45-49 years)

Some also spoke about the negative side effects they experienced during their treatment.

"The course I went on was only 12 weeks compared to 12 months, so it was a much quicker course and it was, it was hard enough. Like a couple of times I wanted to give it up and a few people on the group talked me into keep going ..." (Richie, age 40-44)

"Yeah, it was like being sick all the time. But it was three months of taking a pill. And I know a load of people as well that have gone through it and they couldn't hack just going through that treatment either, they were taking street pills to calm the brain down and so forth." (Leanne, age 40-44)

Other participants told of their plans to seek treatment for hepatitis C.

"I have an appointment in a month so I'll get it done then." (Dillon, age 35-39)

"Yeah so the effects (of hepatitis C) would be just really, what do you call it, fatigue, like tired, no appetite and very bad sleep. I've never had treatment, no ... like I'm an idiot for not going like but I'm still connected with the hospital so I just have to ring and make a new appointment." (Ciara, age 40-44)

Reports of acute illness, either currently or in the past, were associated primarily with infections (n=9), often linked to injecting drug use and/or accidents or incidents (for example, an assault) that led to hospitalisation (n=8). Three participants reported acute gastro-intestinal problems and a further three had undergone surgery in the recent past.

Everyday health problems were also routinely mentioned by participants, with ten reporting the experience of either significant or acute pain. Back pain was reported by a number but, more frequently, participants talked about localised joint or muscle pain, which they said led to sleep interruption and general discomfort. A smaller number described more severe pain, highlighting ways in which pain impinged on their daily lives, their mood and ability to cope with routine tasks.

"You see I suffer from pain and the doctor gave me painkillers the other day. I've been telling the doctor for years that there's something wrong with me – I'm waking up at five o'clock in the morning rolling around in the bed with shooting pains ... I have to get up sometimes at six in the morning and take my methadone so that I can get my kids to school." (Deirdre, age 35-39)

Thirteen respondents (seven men and six women) said that they suffered from insomnia, typically describing sleep disturbance or difficulty initiating or maintaining sleep. These participants also frequently described low energy levels, fatigue and irritability. Several reported poor appetite and found meeting their nutritional needs challenging.

"I wouldn't say it's (health) great, to be honest. I'm not eating good at the minute. Well I actually started eating properly again now the last week or so. But I'm not eating the way I should be eating. I don't eat breakfast. Then I have something to eat maybe about 10 o'clock at night, sometimes a bowl of porridge." (Noel, age 35-39)

"Yeah they're (eating habits) really bad, like I haven't ate anything all day, I've ate a bar of chocolate. Now I will be hungry, I'll be hungry later, I will eat a dinner now and I'll have a few biscuits or something but I could go, I could even go without eating a dinner some days." (Ciara, age 40-44)

When discussing physical health, some referred to their drug use histories, as well as to (sometimes lengthy) experiences of homelessness, which they considered to have seriously impacted their health.

"Years of living on the streets has left me, I feel it in my legs as well. I'm very underweight, I have been for a long time ... I think, all in all, it's left me in a bad way, you know." (Alvin, age 40-44)

Others discussed health-related anxieties related to physical symptoms, leading a number to question the impact of long-term methadone consumption on their health.

"I used to walk a lot but I can't walk normal now. I don't know whether it's paranoia but I keep getting shooting pains into my heart. I don't know if that's me thinking, 'Oh my god I'm gonna have a heart attack'. It's like in your head you're thinking, 'How's this going to end?'" (Bernie, age 40-44).

"I feel alright but, I don't know? It's hard for me ... I wake up, like it does take me a while to wake up, like it takes me a while to get going because of the methadone ... I feel ok but I'm sure, I mean, it's having some kind of effect, you know what I mean." (Eric, age 35-39)

Dental deterioration and the loss of teeth was reported by a large number and was a source of acute stress and anxiety, particularly among the study's women, who reported embarrassment and a lack of confidence arising from their poor dental health: "I'm after getting my false teeth done ... so that's after knocking my confidence a good bit because your smile is your you know, oh god, that's knocked my confidence" (Catherine, age 40-44).

When asked to 'rate' their physical health during interview, a majority (19 participants) described their health status as either 'good' or 'improving', perhaps contrasting with the extent to which chronic, acute and everyday health-related conditions and concerns were reported. This may suggest that a large number of participants had low health expectations or had, alternatively, normalised ill-health. However, very often, participants' perspectives on their health were perceived and assessed in relative terms, with a number recounting health gains and a better ability than previously to perform everyday activities or tasks.

"I went from a person who couldn't get up in the morning, couldn't shower, to somebody that showered every single day, that brushed their teeth, that had clothes and stuff and all of that." (Seán, age 50-54)

"Yeah, I'm finding my own self back. I'm not one hundred percent but three-quarters." (Stephen, age 40-44)

"I can go places and I can live my life without having to wake up every day and look for heroin all the time. That's gone, don't have to feel like I'm stuck with that. I can get up and go out." (Chris, age 35-39)

A large number of the study's participants lived with chronic or acute health conditions associated with their drug use histories, including the effects of polydrug use and infections. Everyday health problems, particularly pain and insomnia – combined with poor nutrition – also impacted quality of life. Although a large number rated their health as 'good' or improved, many also described physical health problems or symptoms of ill-health as a source of considerable anxiety and stress.

Mental Health

A complex range of mental health problems were reported by the study's participants, with only one stating that they were not currently experiencing mental health issues. Noteworthy perhaps is that, in general, participants demonstrated greater openness to discussing mental, compared to physical, health as well as strong ability to articulate the effects of poor mental health on their everyday lives and on their ability to engage in routine social activities.

The most commonly reported mental health problem was depression – reported by 19 respondents – and eight of these participants also experienced 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 of a large number with participants frequently making reference to lifelong mental health problems that sometimes spanned from childhood. Alvin (age 40-44) explained that he had seen a counsellor once weekly as a teenager and that he had also attended a residential psychiatric assessment service for a six-month period. He did not feel that these interventions had helped him.

"But they never really told you anything ... sat you down and explained anything to you or told you what you were going through (pause) ... being made to go to these places and doing all this stuff, you know. It left you feeling a bit, 'What's wrong with me?' sort of thing, you know." (Alvin, age 40-44)

Lorraine also explained that she had suffered depression since her teenage years.

"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)

Like Lorraine, others made reference to lifetime experiences of depression alongside periods during which their symptoms had eased or felt more manageable.

[And what about psychologically, your mental health?]

"Well I suppose depression, I always have done over the years. That just comes and goes but that's from when I was younger. But, no, I'm good now at the moment, do you know." (Yvonne, age 40-44)

However, a large number continued to struggle with depression and anxiety as well as with feelings of low self-esteem and self-worth. When asked about her mental health at present, Catherine (age 40-44) responded: "Very, very, very depressed. Very, very anxious, a lot of anxieties that I would never had before ... I'm having a really hard time, like I'm battling to leave the house". Stephen's (age 40-44) response was similar: "I wake up with a ball of anxiety in my belly every morning". Noel also described current experiences of acute anxiety and stress while Alvin characterised his mental health as "not good", explaining his ongoing struggles with social interaction.

"Stress, I have that, and I have anxiety. I get real bad anxiety, I'm talking bad anxiety where I get sick sometimes ... Like even yesterday one of the guys (in homeless accommodation) that I didn't even know, he was like, 'Jesus man, your mind is racing, isn't it? Relax bro'. I don't even know why I was like that. It's just, you can't even predict it ... like I'm in bits the last while, like bad, really stressed out." (Noel, age 35-39)

"My mental health is not good, I don't think it is anyway. You know, I do struggle with being around other people. Just in general it's not good." (Alvin, age 40-44).

Very many talked about periods when their mental health had deteriorated significantly, often coinciding with traumatic life events or experiences. Bereavement featured strongly in these accounts, with several citing the loss of a child or parent(s) as leading to a steep decline in their mental health. Some had experienced the loss of more than one family member in recent years.

"My baby died. So I couldn't make head nor tail of that ... I ended up depressed. I didn't know what I was, to be honest with you, I just felt very low, very lonesome ..."
(Ciara, age 40-44)

"Yeah I was depressed alright for a long time after me Ma died. Like when me Ma died it was the first time I ever cried like. When other people died, I didn't cry I just screamed aloud, when he died, me brother. And me Uncle, me Granda, I never cried. But the time when me Ma died that was the first time I ever cried like." (Craig, age 35-39)

"I've lost two kids. I've had my own traumas." (Cormac, age 35-39)

"Mental health's not the best, with all these tragedies. I just, I'm not sure how to get out of it." (Danny, age 40-44)

Other triggers for depression and feelings of hopelessness included periods during which drug use dominated participants' everyday lives.

"I've suffered with depression all through my drug use, all through my addiction, depression. When the penny dropped that I was a fuckin' drug addict ... there's not much bleedin' hope there ... the hope and happiness leaves you, sort of. Really, them feelings become, you don't use them as much as you use misery and you run on ..."
(Cormac, age 35-39)

Equally, the personal, social and relational adjustments associated with entry to, or resumption of, treatment led to private ruptures. Seán is one of a number who discussed the challenges that surfaced at the points of engaging or re-engaging with treatment. His account illuminates the range of psychological, social and relational problems that emerged for many along their treatment paths.

"I was lost again in recovery, going to meetings, doing services, doing all the things that I'm supposed to do but inside I was dying again. When you get clean, the best thing about getting clean and the worst thing about getting clean is getting clean. You don't know what's wrong with you. All these things that drugs suppressed come back – emotions and stuff and you have no social skills – you know, people don't talk to you, you take it really personal. You don't understand what's happening, you don't understand the transient nature of stuff, of some relationships. It's all just learning and it's very hard." (Seán, age 50-54)

Housing precariousness was a source of anxiety for two participants: "I have anxiety about the uncertainty of the housing situation" (Ciara, age 40-44). Many others worried about becoming homeless (again) while Richie told of the extreme stress associated with a recent period of homelessness.

"It's not even the fact that you're sleeping in a tent, it's the mindset it puts you in. There's no hope for you, you have no hope for yourself ... and you're just giving up. Because I'd get out of my tent and I'm looking at the beach and the sea and all, but it was all just pretence. Like I was depressed to bits, I was on the verge of suicide."
(Richie, age 40-44)

Thus, for a majority, mental health problems – most often related to depression and anxiety – were ongoing, irrespective of participants' individual circumstances or the specific details of their biographical pasts. A small number described improvements in their mental health as well as positive coping strategies, which centred mainly on activities including walking, reading or physical exercise.

"I do feel down but I mean it's just something that I'm learning to snap out of. I mean the only one that's doing that is me to myself. Get up and go somewhere, take the

dog out for a walk so I'm alright." (Chris, age 35-39)

"At the moment I think my mental health is alright once I keep getting out of this building (homeless accommodation) and going for walks." (Leanne, age 40-44)

"As soon as I started here (community and voluntary sector addiction service) I felt a lot better. Before I started here I could have easily, like I was on the verge of a breakdown." (Richie, age 40-44)

Rachel said that she used a mix of coping strategies during episodes of depression.

"I kind of go into depression, it's not even depression, I just sort of withdraw for a few days ... but I do things to help myself. I'd go for a long walk, I'd go to the gym, I'd go to yoga or meet a friend. Well it would be more going to the gym and going for walks, actually, because I really withdraw." (Rachel, age 40-44)

While Rachel was able to use positive strategies, she also talked openly about her tendency to "withdraw", a commonly stated coping mechanism among participants who told of disengaging or self-isolating during periods or spells of depression. Noel explained that if he was feeling "down", he preferred to "just be on my own and then hopefully tomorrow, the next day, I'd be ok", also remarking that "sometimes I'm not". He elaborated, wondering if talking to someone who had similar experiences might help.

"I don't know if I need to talk to someone who's gone through the same as what I've gone through. I really do not know? I've told my doctor and I thought they'd probably prescribe me something like where it would make me better, make me able to communicate with people instead of staying away in a corner, saying nothing, hope you don't cop on that I'm here." (Noel, age 35-39)

Another commonly reported coping strategy was self-medication. At the time of interview, 14 of the study's participants reported the use of benzodiazepines and only two had been prescribed this medication by their doctors.

A number had requested medication from their doctors and had been refused. Therefore, a majority who used benzodiazepines sourced these drugs on the street or through peer networks, often to alleviate psychological distress, typically associated with anxiety, sleep disturbance and, in some cases, panic attacks: "I'd rely on tablets, anything I could get my hands on – Dalmane, Valium, whatever the hell" (Bernie, age 40-44). Cormac described a complex mix of reasons, including experiences of anxiety and stigma, for his current use of benzodiazepines.

"I buy them (benzodiazepines) on the street ... The life I've led, you know. I've so much anxiety, I fight with my mind every day ... It (addiction) leaves a few mental scars and I beg anyone to challenge me on that, that isn't fairly messed up from it all and that's where the Valium comes in for me because, you know, I get flashbacks. And sometimes I've had to worry about how, you know, even though I'm doing well now and people see it, it's still in the back of my mind like if I go somewhere, 'Ah there's himself, the junkie.'" (Cormac, age 35-39)

Some participants commented on both their physical and mental health, making connections between the two and also with their (negative) coping strategies. The behavioural cycles and responses associated with the health challenges that many faced were difficult to break, as Catherine's account illustrates.

"Well, because its (appetite) not great, my physical health is suffering. I'm not eating great, I'm not sleeping properly, not eating properly, I'm not moving, I'm staying in. I'm spending a lot of time in bed." (Catherine, age 40-44)

These cycles and responses also negatively impacted participants' ability to seek help. Noel told of the ways in which depression and anxiety impacted his ability to feel motivated to engage with services and support.

"I got a list off the doctor and numbers for counselling and, the doctor, after all the work of doing that, I was so depressed, it's just that I couldn't even do it. I have the form up there and all I done was put my name on it." (Noel, age 35-39)

Health and Social Care Service Utilisation and Engagement

As might be expected given the duration of participants' engagement in MMT, a majority reported lifetime contact with services beyond those associated with clinic or GP attendance. More than half had engaged in either individual or group counselling at some stage, four had attended a psychiatric service while a majority had been supported by a keyworker at some point in their lives. Four participants had received parenting support and a large number of others reported engagement with community and voluntary sector addiction services along their trajectories through treatment.

However, at the time of interview, almost half – 12 participants, including seven women and five men – reported that they had no contact with support services beyond their attendance at a clinic or primary care practice for their methadone prescription. The remaining participants (n=13) tended to report engagement with more than one service or support group. Six (five men and one woman) were currently attending counselling, three were engaging or had recently received parenting support, five (four men and one woman) attended a self-help or user group such as Narcotics Anonymous, Alcoholics Anonymous or Cocaine Anonymous, while six (five of them male) were accessing a community or voluntary sector service for individuals affected by substance use. Thus, among this study's participants, reported levels of service utilisation were quite divided; largely a case of all or nothing, with respondents either reporting regular engagement with one or more support service or, alternatively, having no service involvement. Significantly, seven of the nine female participants reported no service engagement beyond clinic or GP attendance for MMT.

Those who were currently attending a community and voluntary sector addiction service discussed numerous ways in which these services provided an environment that supported their efforts to re-build their lives and 'recover'. A number specifically noted their relationships and interactions with their keyworkers and others in the service, which they depicted as positive and enabling.

"So they (staff) just helped us to get the tools to do all of that and we had a key worker here as well so a good few of the people that I was in that group with were aiming to get clean so they've such a great success rate in this building. Like I love this building and I think it's great for people in recovery and people that's trying to just change and stop and move on, that the support here is just out of this world."

(Rachel, age 40-44)

[And do you think you could be supported better?]

"Not by the clinic, no, because (pause) ... I just think the supports are horrendous there like, you know. No. But here (community and voluntary sector addiction service), really, if I hadn't of met (keyworker) ... I think, I'd give a lot of credit to (keyworker), because he puts his heart and soul into you. And the staff here (at the service) are great, you know?" (Cormac, age 40-44).

Dillon talked about the benefits for people who "are out there in the clinics" of having professionals who listen and respond in a non-judgemental manner.

"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).

Participants had access to counselling support in these services which a number said had helped them to deal with long-standing issues in their lives: "I'm bringing up some stuff from the past that has to be brought up, you know" (Stephen, age 40-44). Counselling was helping Cormac to better understand and 'label' the challenges he faced while Richie reported mental health gains arising from his participation in counselling.

"They (professionals in community and voluntary sector addiction service) got me into counselling ... I've availed of that, you know, and I found it very, very beneficial because it's good to understand what's happening to you. Because when you say, 'My head's fucking wrecked' and you're all, 'Why?' and 'What?', you know, it's good to have a label on something." (Cormac, age 35-39)

[And you say it's been good for your mental health coming here (community and voluntary sector addiction service)?]

"Yeah. The counsellors here are brilliant. I have my keyworker, so I'd speak to him every Thursday, just the two of us, and we'd have (pause) ... we'd go over what's been going on for the week. Like when I had my little slip there a few weeks ago." (Richie, age 40-44)

There were others, however, who did not benefit from counselling and these participants tended to hold very negative views on 'talk therapy'. They particularly disliked the emphasis placed on the probing of past experiences, which they found difficult, leading a number to disengage. These participants were typically not currently engaging with services beyond those associated with their scheduled clinic attendance.

"Oh I've done counselling but I felt it made me worse. I'd come out just feeling worse, yeah. Talking about stuff I didn't want to talk about, you know ... I found it hard ... you've to start when you were younger and you don't want to start there. Just prefer not to go there. So I've done it but I don't really think it helps me." (Yvonne, age 40-44)

"Counselling would have been a few years before that but then I tried the counselling again in order to get into the treatment – you had to do the counselling. I didn't like it at all so I just ended up leaving that ... It brought up a lot of bad stuff that I wasn't dealing with properly, looking back on it now." (Alvin, age 40-44)

The accounts of participants who were not accessing services and support suggest that non-engagement had many complex dimensions. Some, for example, had withdrawn from services because they felt that mixing with other drug users was counterproductive.

"I didn't want to be around people that I knew had connections to drugs and stuff like that and wanted to be, if anything, around people that were getting away from drugs." (Chris, age 35-39)

For women in particular, managing the perceptions and expectations of others – including individuals in their community, family members and friends – acted as a barrier to service engagement. Deirdre spoke of her efforts to conceal her attendance at the MMT clinic from others.

"I'm always hoping there won't be many people in (the clinic) so I go down at a certain time knowing that's the time there won't be many there and I'm in and out in a flash like"
[And do you mind being seen going into the clinic?]
I do. Now that actually gets to me, yeah, because everyone thinks that I'm clean, off everything ... my friends, neighbours, old neighbours from (estate where she grew up). Everyone thinks I'm off everything." (Deirdre, age 35-39)

Other women similarly described the use of strategies they hoped would serve to protect them from (further) public identification as a drug or methadone user. For these participants, service engagement represented a threat because it could potentially expose the reality of their lives to others in the community. Indeed, some described their participation in MMT as shrouded in secrecy and concealment¹⁰.

"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"

Several women articulated an awareness of their support needs but most felt that help was not available. Yvonne's perceived needs were focused strongly on the everyday, including

10) We have not attached a pseudonym or age range to this excerpt in the interest of protecting the anonymity of this study participant.

exercise, a desire for a healthy lifestyle and “something to do”. Her account illustrates the extent to which she and others struggled to achieve these goals.

“I’m so down at the moment and when I tell any of my doctors that I’m down and I’m suffering from anxiety straight away it’s, ‘Oh she’s looking for fucking drugs.’ I know that they (drugs) are not the answer for me. I need exercise. I need healthy living. I need something to do. And these are the things that would help people like me who don’t know what else to do. You know?” (Yvonne, age 40-44)

Stigma, often combined with mental health challenges, made service engagement challenging. Lorraine, who also concealed her MMT from family members and others, struggled to engage in activities or to embrace a routine that could potentially contribute to improved mental health.

“I find it hard to motivate myself to do pretty much anything. Even stuff that would be good for me, if you know what I mean? So I’m probably keeping myself in this sort of state ...” (Lorraine, age 40-44)

Social isolation impacted both men and women, acting as a strong barrier to service utilisation. Dillon, who was attending a community and voluntary sector addiction service, commented on the extent to which he had observed the isolation of MMT clients.

“I know a lot of people that are doing that like, they just stay at home like, they’re just isolated to bits like, you know. There needs to be some sort of activity or something like for people to get involved ... I’m sure like it would get people out of the house more and get them more wanting to get involved. Instead of just giving them their Phy every day and sending them on their way.” (Dillon, age 35-39)

For others, service access – and the personal initiative required to source and commit to attendance – presented challenges. Cormac’s account provides considerable insight into the ‘journeys’ that some had embarked on in seeking services and supports beyond the clinic.

“I’ve had to look for help because the clinics let you down. They shut every door. You have to go outside and find it through people that are in recovery and there is good people, you know. You kind of, you have to find your faith in people again ... and like there’s great places but to get into these places, right? It’s a long slog to get into them and it’s not about just getting up and doing it because during that journey, you can get very deflated.” (Cormac, age 35-39)

Overall, reported levels of service utilisation and engagement were mixed, with only approximately half of the study’s participants reporting the use of services and supports apart from clinic or primary care practice attendance for their methadone prescription. Stigma and social isolation emerged as strong barriers to healthcare access and utilisation, particularly among women who frequently sought to conceal their methadone use from family members and others in the community and who feared that service engagement would jeopardise their efforts to shed a drug user identity.

The Meaning of 'Recovery'

Particularly in more recent years, 'recovery' has become central to international drug and alcohol policy, even if, as documented in Chapter 2, Irish policy makers opted to use the term 'rehabilitation' rather than 'recovery'.

The concept of recovery carries diverse meanings and there is, in fact, little consensus among researchers, policy-makers or service providers on what it actually means (Best et al., 2009; Betty Ford Institute, 2007; Laudet, 2007; Neale et al., 2011, 2015; Thom, 2010). Recovery is frequently equated with abstinence from all substance use, thus potentially clashing with and undermining the philosophy of services that operate within a broader harm reduction framework. As Neale et al. (2014: 311) point out, "[w]hether or not opiate maintenance treatment can support recovery or is evidence, per se, of a failure to achieve recovery has also been widely disputed". However, amidst ongoing discussions and debates, there is an emerging consensus that recovery means more than mere abstinence or a reduction in substance use; rather, it goes beyond substance use and involves the achievement of personal and social goals in different areas of life including housing, employment, relationships and community participation (ACMD, 2013; Laudet, 2007; Neale et al., 2012). It may be argued, therefore, that the concept of recovery has much in common with the notion of social reintegration.

Engaging people who are MMT clients about the meaning of recovery is important since service users have detailed knowledge and understanding of their personal situations and of the experience of treatment (Laudet, 2007; Neale et al., 2015). During interview, participants were asked about their understanding of the term recovery which yielded rich accounts of their perspectives on what the term or concept meant to them. The meanings attached to recovery were also captured through discussion of participants' perceived needs, their perspectives on MMT and aspirations for the future.

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)*

Yvonne went on to say that she felt that she was now "addicted to methadone" and elaborated by explaining that she did not feel "recovered".

"I just feel like I've moved from one thing to another, you know. I'm not addicted to gear anymore, I'm addicted to methadone. I'm still like an addict. I don't feel like I'm recovered and I'm clean because I think I've just passed my addiction to another addiction. Instead of trying to cure my addiction, they've just changed it to another addiction." (Yvonne, age 40-44).

Several others expressed a desire to become methadone-free, using terms such as "off", "clean" and "healthy" to convey their perspectives on recovery.

"Ideally I'd love to be able to sit here and say, 'I'm off methadone.'" (Bernie, age 40-44)

"(Recovery) means I'm clean and healthy and happy and I'm going in the right direction, that's what it means to me." (Eric, age 35-39)

"I just want to get a gaff (house or flat), get off this methadone and just get my life back together." (Conor, age 35-39)

Thus, for a number, recovery incorporated a desire for an opiate-free life without methadone dependence. However, as the above excerpts illustrate, most who placed a strong emphasis on this goal also referenced broader aspirations such as an ability to move forward with their lives ("going in the right direction") or the hope of reclaiming something that they had previously ("get my life back"). Noteworthy also is that, for some, the goal of becoming methadone-free did not necessarily mean drug-free. Explaining that he was "in recovery", Cormac expressed a desire to "come off" methadone, also remarking that becoming methadone-free was a "long journey".

"I want my life back ... I'm in recovery trying to do the day programme, getting the meetings in ..."

[And what's your motivation for wanting to come off (methadone)?]

"I've something to lose now, there's like, you know, I've (pause) ... I'm living with guilt and shame too long now and I just feel in myself, I'm not the worst of people ... I want to be free of it and all, but like I said it's going to be a journey, a long journey." (Cormac, age 35-39).

He did not, however, rule out the use of other substances.

"... but at the end of the day I'd be comfortable if I was on a few Valium for the rest of my life even if like off the methadone ... Once I'm happy and comfortable and I can live a productive, constructive life, even if I have to take a few Valium, I'll accept that, you know." (Cormac, age 35-39)

As might be expected, participants' drug use and drug treatment histories influenced their perspectives on recovery, which were also subject to change over time. For the sample as a whole, the theme of "getting clean" – whilst threaded through the narratives – did not, in fact, dominate discussions about recovery. More often, participants' narratives emphasised a process or journey that they hoped would result in a more fulfilling life, a return to stability and the resumption of key roles and relationships. For Stephen, recovery meant "getting better" and living "a normal life", which he linked with finding stable housing and seeing his children.

"Recovery is getting better. Recovery is recover, get better from this ... And just live a normal life, live a normal life. I'm on the list, I don't know how many years on the list to be housed. I'm not saying I should be housed or anything but just, if those things – to be having a small little two bedroom house and have my children and that would be just my life." (Stephen, age 40-44)

Somewhat similar to the notion of "getting better" expressed by Stephen, for Dillon, recovery meant to "mend" or "fix"; to change his thinking and "way of doing" and to recover his body and mind.

[And so what does the word recovery mean to you?]

"It means to mend myself, I suppose mend parts of me that seem to be kind of out of place, that needs to be fixed, kind of thing, you know. Change my way of thinking and change my way of doing. Recover my mind, recover my body. That's what it means to me anyway ... Recovery is like fixing, mending, you know what I mean." (Dillon, age 35-39)

For others, recovery was strongly linked to redeeming or wanting back what they had, or could have had, prior to their drug dependence – a home, positive family relationships and contact with family members.

"I want my own place (home) ... I want my life back basically. To me, a normal life is having my own place and my family back in my life. That's it, that's all I want. Even if I could ring my ma once a week, once a month and say, 'Love you', and she goes, 'Love you back', and hang up. And see my nephews and nieces." (Noel, age 35-39)

"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)

Some participants were less certain about what recovery meant to them. Alvin, for example, mentioned "getting clean" alongside other aspirations linked to dealing with the past and seeking employment before pausing and expressing uncertainty.

[So, at the moment, what does the word recovery mean to you?]

"I suppose beyond just getting clean, you know, getting clean, dealing with issues from the past and moving on, maybe trying to get some employment further down the line (pause) ... I don't know really? Sorry." (Alvin, age 40-44)

He went on to explain that he was "trying to deal with the here and now and get through each day", which made looking to the future difficult.

"You don't know where you're going to be in another year so, if I can do it, I'll just keep coming here (community and voluntary sector service) and see how it works out. I'm trying to get clean and I don't really know what to expect." (Alvin, age 40-44)

Conversations about the topic of recovery frequently led participants to revert to discussing their experiences of treatment which many characterised as lacking compassion and care (see Chapter 5 for a detailed analysis of participants' experiences of MMT). For Yvonne, clinic attendance did not equate with 'treatment'.

"There's no treatment, there's nothing there, because half the time they (doctors) don't even wanna talk to you, they just want to, 'Give us your urine, there's your script, see you in a week'. So it doesn't seem like you're in treatment, it doesn't feel like they really want to help you. They don't say, 'Oh well we've got this, or you could try this, or maybe you could (pause)'. You don't get any of that, you know." (Yvonne, age 40-44)

Tensions between what participants wanted or aspired to and what they had observed throughout the experience of MMT were embedded in the accounts of others who, like Yvonne, questioned the relationship between treatment and recovery. Dillon said that he wanted to "go out into the world" and improve his life but noted that, for most, these broader goals are not addressed by a service system that 'holds' people on methadone.

"I want to be able to go out into the world and further myself and get work and like there is people that can, that are doing it. But the majority of people are just being held in one spot. They're not helping them, they're just giving them their Phyllo and sending them on their way." (Dillon, age 35-39)

When asked about recovery, Bernie talked about "freedom" and "peace of mind", referring to the possibility of dealing with "ordinary" or everyday problems and not with the "chemist and clinic" problems that had come to define her life.

[What about recovery? What does that mean to you?]

"It means freedom. It means having a job. It means peace of mind. It means having problems but not major problems, it means having ordinary average problems, not having to go to the chemist and clinic problems. Just ordinary problems – I'm a bit short for rent this week or trying to budget, just normal stuff, and not having to answer to somebody ... I just want away from all that." (Bernie, age 40-44)

Lorraine did not want to be perceived as "arrogant or ungrateful" but, for her, MMT was the antithesis of recovery.

"I imagined, you know, with sort of treatment, the ultimate goal is to be drug free and to stay drug free. Not to be given a synthetic opiate for the rest of my life. And it's just, I don't want to come across as ungrateful, I'm glad there's any sort of treatment there for someone like me that makes these choices. I don't mean to be sort of so arrogant or ungrateful but it's pointless nearly." (Lorraine, age 40-44)

She went on to discuss the meaning of recovery, which she said had been a prior goal but now had no meaning. Recovery, according to Lorraine, was not, in any case, part of the drug treatment system with which she was engaged which she characterised as focused on "maintaining the status quo".

[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)

Just four study participants used the term "in recovery" to describe their current situations: "I'm in recovery, it doesn't bother me in the least so I'm not tempted and I've a good life" (Sean, age 45-50). Another participant, Ronnie, who talked at length about his efforts to address depression along his treatment path, discussed multiple dimensions of recovery

beyond those associated with reducing or ceasing substance use.

“... so there was a lot of recovery. It wasn't just about putting away the drink and the drugs for me. It was about getting right in there and finding out why I would have started going down that road in the first place, you know. So a lot of work has been put into my recovery.” (Ronnie, age 45-50)

While participants' accounts of recovery varied, most expressed treatment and recovery goals and aspirations that extended far beyond those associated with a reduction in, or cessation of, drug (including methadone) consumption. A majority placed a strong emphasis on the attainment of relationship and familial goals, improving personal well-being and a desire to participate in everyday life in their communities. Participants' perspectives on recovery frequently overlapped or intersected with their experiences of MMT, which many felt did not support the notion or concept of recovery.

Conclusion

A majority of participants in this study were dealing with complex life problems and vulnerabilities that compromised their physical and mental health and well-being. In keeping with the existing literature on older or long-term participants in drug treatment (Ayers et al., 2012; Doukas, 2011, 2017; EMCDDA, 2010; Rosen et al., 2008), a large number reported both chronic and acute physical health conditions as well as mental health disorders and challenges that significantly impacted the quality of their lives. Many were susceptible to self-isolation as a coping strategy (Roe et al., 2010), which exacerbated their mental health difficulties, 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. The multiple and complex health problems reported by the study's participants point strongly to the interconnectedness of the medical, psychological and social needs of individuals who are long-term clients of MMT (Doukas, 2017).

The findings presented in this chapter also highlight the numerous access-to-care issues faced by long-term MMT clients. Irrespective of gender, service access and participation was challenging, with both men and women reporting experiences – often linked to depression and isolation – that constrained their ability to engage with services and supports. Particularly prominent was the extent to which women were not accessing services beyond clinic attendance for their methadone prescription. However, studies have shown that women can encounter particular barriers – such as negative stereotyping, social stigma and lack of childcare – in accessing support for their drug problems (Copeland, 1997; Fraser, 1997; Nelson-Zlupko et al., 1996). The findings presented here suggest that MMT stigma prevented service utilisation among the study's women, often because of a felt need to conceal their methadone user status. Service engagement conflicted with the goal of concealing methadone use because it could potentially expose a stigmatised and stigmatising drug or methadone user 'identity' to others in the community.

Finally, participants' recovery narratives are revealing – providing important insights into their perceived needs – and also demonstrating that people who use drug services are able to articulate their views and perspectives (Neale et al., 2014). To a large extent, participants' accounts speak to the multi-dimensional nature of recovery but, equally, to recovery as an experience “embedded in a broader biographical and social context” (Neale et al., 2015: 32). While a considerable number depicted recovery as 'getting clean', including the goal of living a methadone-free life, recovery was more often depicted as a process of self-improvement and a journey towards a new and better life. Some framed recovery as getting back or regaining something that they had lost, as “becoming what they were meant to be before they started using drugs” (Laudet, 2007: 13). Significantly, for a considerable number, the experience of MMT was perceived as thwarting these recovery goals, not simply because of the 'bind' of methadone but also because 'treatment' was focused primarily on the administration of a substitute drug and not on their broader health and social care needs.



CHAPTER 8

Discussion and Conclusions

This final chapter discusses the study's findings in light of the literature reviewed in Chapters 1 and 2. A number of conclusions suggest themselves but perhaps the overriding conclusion is that for this study's participants, the drug treatment system as it currently exists has failed to normalise addiction as a medical condition and, more specifically, has failed to normalise methadone treatment as an evidence-based healthcare intervention. Later sections of the chapter consider the theme of ambivalence, followed by a discussion of recovery and social reintegration; ageing, methadone maintenance treatment and health; stigma and its consequences; and the management of addiction within the healthcare system. As a starting point, the study's focus and aims are revisited with attention directed to the strengths and limitations of the research.

The Research

As outlined in Chapter 1 and elaborated on in Chapter 3, the research aimed to examine the experiences of individuals who are long-term participants in methadone treatment programmes. At the core of this qualitative interview-based study was a commitment to collecting and analysing service users' perspectives on MMT. The interviews also sought to address a broad range of issues beyond methadone treatment: physical and mental health were discussed in detail as were participants' social lives and relationships, their economic and housing situations and the extent to which they were engaged with drug treatment and other health and social services. Drug treatment service users clearly have detailed knowledge and understanding of their situations, health status, personal aspirations and their social and service needs; their perspectives are critical to informing service provision and policy that may otherwise be somewhat detached or disconnected from the realities of their lives and the nature and complexity of the problems they seek to address (Neale et al., 2015).

The findings documented in the previous four chapters provide a detailed, contextualised account of the study participants' experiences of MMT. Clearly, however, the sample size is small and caution is therefore needed when generalising this study's findings to other populations who are long-term clients of methadone treatment. It is also important to reiterate that a majority who participated in this research were attending specialist addiction clinics, a

client group that may have less stability in their lives and a greater number of vulnerabilities than others who attend primary care settings (Department of Health and Children, 2005). It is possible, therefore, that a more positive picture of MMT might have emerged had a larger number of participants been recruited from GP practices. Nonetheless, research in the Irish context that has examined methadone clients' experiences of treatment within primary care settings has produced mixed findings, documenting satisfaction with prescribing practices but far from optimal levels of involvement in decision-making about their treatment plan (Latham, 2012; O'Reilly et al., 2011). However, questions might be raised about why, more than ten years subsequent to first accessing treatment for heroin dependency – and close to twenty years for a majority – this study's participants had not transitioned to primary care settings. This study's findings are therefore particularly important in understanding the experiences of long-term MMT clients who, by virtue of the duration of their treatment and continued interaction with specialist addiction services, are potentially among the most marginalised clients of methadone treatment.

Explaining Ambivalence

In keeping with the findings of previous research that has examined client experiences of opioid substitution treatment (Fraser & Valentine, 2008; Harris & McElrath, 2012; Radcliffe & Stevens, 2008; Van Hout & Bingham, 2011) the service user perspective presented in this report was essentially one of ambivalence. While a large number of participants conceded that MMT had conferred benefits and perhaps even saved lives, they simultaneously expressed hugely negative sentiments about methadone and the treatment system within which methadone is embedded. In many ways, the criticisms of the service users interviewed mirror those emanating from research that has examined the perspectives of stakeholder groups: rather than being seen as a valid and enabling treatment, methadone was viewed as a form of social control by the state that maintains the status quo – trapping service users into life-long addiction and impeding their prospects of full and meaningful participation in society.

While methadone – as a substance and substitute drug – was subjected to strong critique by many of the study's participants, much of the ambivalence attached to MMT can be explained by their interactions with treatment services and clinics, their prescribing physicians and other professionals associated with the regime of methadone maintenance. While acknowledging the kindness and empathy of some professionals with whom they interacted in surgeries, clinics and pharmacies, participants did not generally view their experiences in positive terms. The treatment experience 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. Trust had to be earned and was accomplished only if, as clients, they demonstrated 'good' behaviour – strongly connected to providing 'clean' urines – and was easily and even abruptly withdrawn in the event of 'slips' or relapse. Power imbalances were therefore very apparent in participants' accounts of their interactions with healthcare providers and acted as a strong deterrent to meaningful engagement. The requirement to provide urine samples under supervision was invariably depicted as an intrusive and dehumanising form of surveillance (Harris & McElrath, 2012) and as

engendering feelings of humiliation, embarrassment and shame¹¹. Perhaps understandably, experiences such as these led to clients feeling sidelined and, particularly over time, MMT represented a “ball and chain”, its meaning tightly bound to stagnation and to a perceived absence of alternatives to a life defined by the use of a substitute drug.

A prominent feature of the treatment experience was a perception that, as clients or patients, they had no say in their treatment. Participants routinely recounted ways in which their interactions with their prescribing physicians were restricted to the matter of the methadone ‘script’, with little or no discussion of broader health-related issues or their treatment more generally. Very many were critical of what they experienced as encouragement to increase their daily dose of methadone but with no discussion of the possibility of a dose reduction or a detoxification plan. By and large, participants felt controlled rather than in control with little evidence of them feeling able or entitled to share their experiences or to articulate any aspirations or needs related to their treatment. This lack of involvement in treatment planning also produced feelings of disempowerment, apathy and resentment. Thus, despite policy rhetoric extolling the virtues of service user involvement and participation in both their own treatment and in the wider policy and service provision arenas (Department of Health, 2017; HSE, 2016), the views of this study’s service users were not routinely sought or, when offered, treated with any great respect or consideration.

Recovery and Social Reintegration

One theme of the literature reviewed in Chapter 2 was that of recovery or, in the Irish context, ‘rehabilitation’. While recovery is an ambiguous and contested concept, it is one that has nonetheless gained prominence internationally in opposition to the concept of harm reduction which, in the wake of the HIV/AIDS threat, had been at the forefront of addiction policy during the previous twenty years. One of the spatial metaphors commonly used in recovery policy documents is that of ‘pathways’: ideally, clients still using illicit drugs or prescribed opioid substitutes should be moved along a pathway to abstinence and full social reintegration. However, it was striking that the methadone users interviewed for this study constantly used metaphors or other linguistic usages that conveyed an opposing image of the experience of addiction treatment. Rather than being moved or assisted to move along a pathway to change and recovery, research participants saw themselves in terms of stasis and confinement – for example, as being “in prison”, “a lifer” or occupying a “holding space”. Many who had previously anticipated an end to their addiction careers and to its management by healthcare services now saw themselves as trapped or indefinitely consigned to a regime that made it difficult, if not impossible, to discuss reducing dosages of methadone or becoming drug free.

As suggested in Chapter 7, the concept of recovery has much in common with the notion of social reintegration, which is concerned with the broader aim of supporting treated drug users’ integration into wider society in relation to education, employment, housing and

11) The HSE’s (2016: 42) Clinical Guidelines for Opioid Substitution Treatment states that “Direct observation of urine specimen collection is not required in routine clinical practice”.

family relationships (EMCDDA, 2012; Keane, 2007; Neale & Kemp, 2010). Among this study's long-term MMT clients, levels of social reintegration can be described as extremely low: the vast majority were unemployed and did not see any realistic prospect of future labour market participation, a considerable number were currently homeless or precariously housed and, while some reported improved family relationships, for others family ties were tenuous and relatively few had family members who were in a position to provide regular or ongoing financial, social or emotional support. Put differently, their 'recovery capital' (Cloud & Granfield, 2008) was low, meaning that most did not have access to the kinds of economic, social or personal resources considered necessary to bolster and sustain the recovery process. To a large extent, the lives and situations of this study's participants echo the evidence presented by the ACMD (2015), highlighting the multiple deprivations and challenges, including unemployment, housing precariousness, homelessness and damaged relationships, that opioid maintained heroin users are likely to confront, and the assertion that recovery, if understood as abstinence, is a very ambitious goal for individuals with a heroin dependency.

Ageing, Methadone Maintenance Treatment and Health

Chapter 1 of this report presented clear evidence of an ageing drug treatment population throughout Europe and indeed globally, including in Ireland. These changing demographics signal new challenges for care providers and have implications for drug treatment and broader healthcare services. Against this backdrop, it is perhaps not surprising that the need to develop responsive policies, treatments and services to support this client group is increasingly recognised (EMCDDA, 2017). While definitions of 'older' drug users vary, it is generally agreed that the ageing process among individuals who are long-term participants in drug treatment is accelerated by up to fifteen years (Matheson et al., 2017).

In keeping with the findings of research in other European countries and in the US (Beyon et al., 2009; Grella & Lovinger, 2011; Johnson et al., 2017; Loftwall et al., 2005; Matheson et al., 2017; Roe et al., 2010; Rosen et al., 2008), this study's participants reported chronic health problems, including hepatitis C, liver cirrhosis and a range of respiratory, renal and coronary diseases. Fifteen (60%) had tested positive for hepatitis C, although a large number of these participants had received, or were currently receiving, treatment for the condition. Acute health problems, often related to infections linked to (past) injecting drug use were also widely reported, as were everyday persistent problems related to pain, insomnia, fatigue, low energy-levels and irritability. While some expressed health-related anxieties, a majority rated their current health status as 'good', often because they felt their health had improved or that they were better able than previously to manage at least some everyday tasks and responsibilities.

Mental health problems were widely reported, with depression being the most commonly cited mental health condition. For a large number, depression was accompanied by anxiety, with both conditions often attributed by participants to their drug use histories and related traumatic life events or experiences. The prevailing picture to emerge was of individuals who

struggled to cope with everyday life and in particular with social interaction, leading many to self-isolate as a coping strategy. Self-medication with street-sourced benzodiazepines was also widely reported. Again, these findings resonate with those documented by researchers of older drug-using populations in other jurisdictions (Beyon et al., 2009; EMCDDA, 2010, 2017; Matheson et al., 2017) and strongly suggest that long-term MMT clients are likely to have multiple physical and mental health care needs compared to younger drug users, which may also create distinct obstacles to engaging this group (Atkinson, 2016).

Stigma and its Consequences

Among the individuals interviewed, the dominant experience of being a methadone user was one of stigmatisation and, for a majority, stigma operated on multiple levels (Coner & Rosen, 2008). At the institutional level, participants described numerous ways in which they felt stereotyped by the treatment settings they attended and disrespected by clinic and pharmacy staff. Although aware of the processes and broader societal beliefs that supported and perpetuated stigma, they felt unable to challenge or 'speak back' to the negative attitudes and stereotypes they confronted. Feeling marked out as less worthy than other health service users, in the classic Goffman (1963) sense, they saw themselves as 'discredited' (or at least 'discreditable') and as having a 'spoiled identity'. Stigma was also experienced by participants in quite distinct ways within the communities where they resided, impacting their experiences and interactions and 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 and rejected because of their continued engagement in MMT.

Stigma negatively shaped participants' lives, both socially and emotionally, and the impact and consequences of stigma were numerous and severe. Stigma diminished quality of life by way of instilling and perpetuating feeling of 'otherness' and shame, negatively affecting self-esteem, self-efficacy and mental health. Stigma also contributed to social isolation with participants frequently discussing ways in which they felt excluded from community and family life. A considerable number reported self-isolation as a response to stigma which exacerbated their sense of loneliness and exclusion.

Finally and importantly, stigma and shame negatively impacted participants' willingness and ability to engage with services (Ayers et al., 2012; Coner & Rosen, 2008; Smith & Rosen, 2009). As documented in Chapter 7, health and social care service utilisation varied but, for the sample as a whole, can be characterised as minimal or low. Particularly among the study's women, service engagement was associated by them with a further risk of public identification as a drug or methadone user which many perceived as a threat and therefore sought to avoid. It has been suggested that, over time, female drug users "may have accumulated more negative experiences that affect their engagement with services" (Matheson et al., 2017: 40). Certainly, the imperative of secrecy and concealment was particularly strong among the study's women and acted as a barrier to service access and utilisation. Irrespective of gender, participants in this study confronted the multiple stigmas of drug addiction, methadone treatment and growing older, leading to negative self-

perceptions and significantly compromising help-seeking and service engagement.

Managing Addiction within the Healthcare System

The literature reviewed in Chapter 2 referred to the historic evolution of addiction treatment within health systems, both in Ireland and elsewhere. The establishment of Ireland's first specialist addiction centre at Jervis St. Hospital in 1969 was influenced by British developments at that time and the Jervis St. centre – headed by a consultant psychiatrist but not within the adult mental health system – reflected, amongst other things, a reluctance on the part of psychiatrists to accept responsibility for the management of a client group commonly considered to be difficult, dangerous and generally undesirable. The emergence of a specialist addiction service in Ireland, as elsewhere, may be seen as an indication of a continuing reluctance by the more established branches of medicine to accept such responsibility. Current mental health policy in Ireland, as set out in *A Vision for Change* (Department of Health and Children, 2006), suggested a hardening of anti-addiction sentiment by mainstream psychiatry and, despite ongoing efforts to persuade more GPs to participate in the methadone protocol, figures from the Central Treatment List consistently show that more clients are being treated in specialist clinics than in GP surgeries or primary care centres.

Difficulties in accepting addiction as a normal, 'respectable' illness or disease are, of course, universal rather than a peculiarly Irish phenomenon. In the classic Parsons' (1951) exploration of the 'sick role', it was argued that sick people were not responsible for their sicknesses and that, by virtue of sickness, were exempted from normal social responsibilities. In the case of addiction, however, even amongst those who accept the causal importance of social risk factors, there are understandable and persistent beliefs that the condition is self-inflicted and that its sufferers cannot be absolved of responsibility for the choices that led to its emergence. Similarly, drug dependent individuals are not routinely exempted from their social duties, nor are they absolved from responsibility – as some psychiatric patients are – for criminal behaviour which is deemed to be drug-related.

While most models of addiction place considerable emphasis on the issue of control and choice, and the extent to which addictive behaviour reflects either lost or diminished control over the decision to use drugs, there is also general agreement that these individuals retain some degree of choice in this matter (Heather & Segal, 2017). In practical terms, what all of this suggests is that there has been little or no progress over the past century in moving on from what Valverde (1998) described as a situation where addiction was neither seen as a physical nor a mental disease but, instead, as a 'disease of the will'. Applying this conceptualisation to the present study, it may be argued that long-term methadone patients are likely to be seen – by the professionals treating them, by the general public and, perhaps, by themselves – as lacking will power.

At present, management responsibility for addiction treatment in Ireland is based within the Social Inclusion stream of the Health Service Executive – which perhaps is a realistic location given the considerable overlap between drug addiction and social deprivation but is a far cry from the aspirations of those who contend that addiction is a disease. Wherever

they are located, however, it is hard to see how any health service initiatives can succeed if it fails to secure cooperation and resourcing from a wide range of external agencies and sectors – dealing with housing, income maintenance, education and training.

Concluding Remarks

The findings presented in this report correspond closely with those documented in similar, albeit larger-scale studies, in highlighting the complexity of the characteristics and needs of drug users who are long-term participants in MMT. Age, combined with the longevity of their drug use and drug treatment careers, means that this client group will present to services with multiple challenging health, social and economic needs. In addition to exhibiting higher rates of both physical and mental health problems than younger drug users or their same-aged peers in the general population, isolation, social exclusion, stigma and loneliness are social consequences that this client group typically face.

Equally and importantly, within long-term methadone treatment populations, difference and diversity clearly exist in terms of experience, health status and the extent to which individuals are engaged, or are willing to engage, with services. Diversity related to gender, age, the duration of treatment and current substance use also need to be considered when devising and delivering effective service responses. If the needs of this client group are to be responded to effectively, it will be important to balance recognition of their multiple and complex needs with an appreciation of clients' unique biographical pasts, their specific economic, social and personal circumstances and their perspectives, and ability to articulate their views, on their current and future treatment needs.



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“Just Maintaining the Status Quo”?

THE EXPERIENCES OF LONG-TERM PARTICIPANTS IN METHADONE MAINTENANCE TREATMENT

This qualitative research examines the experiences of long-term participants in methadone maintenance treatment in one geographical area in Dublin that has an established history of concentrated drug problems.

The study is timely in light of a growing recognition of the specific challenges faced by older drug users who are clients of drug treatment. International research and literature reviews demonstrate older drug users to have distinct physical and mental health issues compared to younger drug users. Such health concerns are frequently accompanied by social issues and challenges including isolation, loneliness, unemployment and housing precariousness or homelessness.

In Ireland, the social and health needs of older drug users are recognised and explicitly articulated in the National Drug and Alcohol Strategy, *Reducing Harm, Supporting Recovery – a health-led response to drug and alcohol use in Ireland 2017- 2025*. It is envisaged that this research will contribute further to bringing focus to the social and health needs of this highly vulnerable group in society.

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