KNOWLEDGE EXCHANGE SEMINAR SERIES

Institutional stigma and the delivery of methadone maintenance: A comparison of clients' experiences from North/South Ireland

Karen McElrath & Julie Harris
Queen's University Belfast (k.mcelrath@qub.ac.uk)

1. The early vision of methadone maintenance

Although methadone was first synthesized in the 1940s, it did not receive significant medical interest until the 1960s when a team of New York medical professionals (Marie Nyswander, Vincent Dole and Mary Jeanne Kreek) were conducting research into opioid (namely heroin) dependence in the US. They found that morphine was inappropriate for stabilising people who were dependent on heroin because morphine dosage levels had to be continuously increased. Their review of the medical literature suggested that methadone was suitable for stabilising opioid dependence – the synthetic opioid was inexpensive, could be administered orally, appeared to be longer acting than morphine and stabilisation could occur from one daily dose appropriate to the user's needs.

Dole and Nyswander believed that heroin dependence was a metabolic disorder that could be treated through a combination of "methadone maintenance" (i.e., prescribed daily use of methadone over the long term) *and*

various psychosocial interventions designed to meet the needs of the individual. These interventions included counselling, educational and vocational training, and ancillary services, e.g., assistance with locating suitable housing. They believed that the pharmacological benefits of methadone were limited unless individuals could experience "social rehabilitation" that would help them address their social, personal and health problems. Part of their vision was to create treatment settings that were characterised by trust. For example, they employed stabilised clients to liaise between mistrustful patients and clinic staff (1960s). Although the number of methadone programmes expanded during the decade that followed, treatment delivery changed considerably from one of trust, to one characterised by strict regulatory controls that often affected therapeutic relationships between service providers and methadone clients. Some regulatory aspects of the US methadone model spread to other countries, including North/South Ireland. This briefing paper addresses methadone clients' perceptions of treatment delivery in North/South Ireland. We suggest that some service provision is characterised by institutional stigma that can negatively affect recovery from heroin dependence.

2. What does the international evidence say about the effectiveness of methadone maintenance?

A vast amount of international evidence suggests that methadone maintenance treatment (MMT) is associated with *reductions* in a) heroin use, b) fatal overdoses involving heroin, c) behaviours that pose risk for HIV and Hepatitis C, and/or d) crime. However, the results from these studies tend to be biased because a number of methadone clients drop out of treatment and

are thus excluded from the studies. Relatively large numbers of methadone clients leave treatment within the first few months, and upwards of 40-60% leave treatment within 12-14 months of commencing it. In other words, retention in MMT programmes "is the exception rather than the rule" (Fischer et al., 2005:3). Retaining methadone clients in treatment is important because treatment outcomes are generally more favourable with longer stays in treatment. Additionally, risk of overdose increases when people leave MMT prematurely.

3. Methadone maintenance in N/S Ireland

MMT provision commenced in Northern Ireland in 2004 (high-dose buprenorphine, i.e., Subutex is an alternative medicine for people dependent on heroin). On 31 March 2010, 466 were being prescribed methadone or Subutex, of whom 52% were in receipt of methadone maintenance. Methadone clients are monitored and tracked via the Substitute Prescribing Database, and the Addicts Index.

In the Republic of Ireland, MMT has officially been available since 1992, although provision was largely confined to the Dublin area until the mid-1990s. Surveillance and tracking of MMT clients are conducted through the Central Treatment List, although various sources provide different estimates of the number of MMT clients at a particular time. One recent estimate suggests that a total of 9,204 individuals were in receipt of methadone maintenance on 1 August 2010.

In both jurisdictions, most MMT clients engage regularly with addiction services (e.g., clinics) and most consume their methadone in pharmacy settings. The pharmacological effectiveness of methadone requires daily consumption, thus several MMT clients negotiate near *daily* visits to a pharmacy. "Supervised consumption" is commonplace and often required, which means that clients consume the methadone in a pharmacy setting in the presence of pharmacy staff.

4. How did we conduct this research?

We "pooled" data from four different studies in which we have been involved. All of the studies used face-to-face interviews to collect data from people who were dependent on heroin, 81 of whom had direct experience with methadone maintenance. Two of the studies were conducted in Northern Ireland, and two other studies took place in the Republic of Ireland (Counties Louth and Dublin). Data from the four studies were collected between 2004 and 2010.

5. What were some of our main findings?

Methadone clients in the four regions voiced concerns over the manner in which methadone service providers (pharmacists and clinic staff) responded to them. MMT clients perceived that they were treated as "addicts" regardless of their stage of recovery. Furthermore, "addict" identities were tied to assumptions about crime and deviance. For example, MMT clients recalled instances whereby pharmacy staff watched them closely as if clients were preparing to steal items from the pharmacy while they were collecting their methadone. Some pharmacies refused to allow MMT clients to enter the pharmacy when the client was accompanied by another adult, and clients

perceived that this rule was enacted because pharmacy staff believed that "addicts" tend to disrupt or steal from the pharmacy setting. Many clients were asked to sign contracts and the continuation of MMT depended in part on how clients behaved according to their contractual obligations. In the North, clients' contracts required them to be punctual for appointments, and advance notice from clients was required to change the appointments. Contracts were signed by the client, the prescriber, the dispenser and the key worker, but the behaviours listed on the contract pertained to the client only. Collectively, these examples suggest that service providers and methadone policies are distrustful of MMT clients.

5.1 Undeserving customers

Several MMT clients felt like undeserving customers in pharmacies and clinics. This finding was reflected through accounts of limited privacy, lengthy wait times and in the ROI, poor facilities. The pharmacy is a setting where MMT clients come into contact with "normal" or regular pharmacy customers. Several clients reported that they were well down the list of preferred customers, and were required to wait for their methadone until regular customers had been served. Some individuals attempted to avoid the stigma of the public gaze by looking at pharmacy merchandise, pretending to be regular customers. Other clients waited outside the pharmacy until regular customers had left.

Some of the clinics in the ROI were characterised by grim, depressing and near-dilapidated external facades. Toilet facilities were described as particularly demeaning at one of the sites in the ROI.

5.2 Lack of client input into decisions affecting treatment

MMT clients felt powerless over several decisions that were made by treatment providers. Some of these decisions involved methadone dosages whereby ROI clients in particular, felt that dosages were too low which deterred them from remaining in treatment. Other ROI clients reported that pharmacy staff had reduced the methadone dosage or had refused to provide the methadone when clients arrived at the pharmacy a few minutes past their scheduled time.

In general, MMT clients believed that they were passive recipients of methadone treatment. For example, a number of clients voiced concern over the possibility of forever being on methadone maintenance. They noted that there appeared to be a blanket policy of keeping people on methadone with no option of reducing the dosage. Gradual detoxification from methadone was rarely discussed with them.

6. Conclusion

Data collected from four study sites suggest that people who participate in methadone maintenance are often assumed to be deviant and treated accordingly. We suggest that attitudes by some service providers derive from stereotypical assumptions about people who are dependent on heroin, and that stereotypical assumptions are fuelled in part by methadone regulations that focus more on controlling "addict" behaviour than treating disease. Institutional stigma can disempower MMT clients, whereas recovery *requires*

empowerment. The prospect of recovery is limited when individuals are devalued by the treatment process itself.

7. Strategies for change

- Reframe MMT provision so that clients are viewed as customers or consumers
- Establish advisory groups of service users who can contribute to the development of anti-stigma interventions
- Introduce patient-focused advocates who can engage in dialogue with treatment providers, dispensers and prescribers
- Alter the institutional identity of addiction services, e.g., "recovery centres" (White, 2010)
- Implement ways to encourage service users to have a stake in programme ownership
- Involve like-minded empowered others in the treatment process

Biographies: Karen McElrath is a Reader in Criminology in the School of Sociology, Social Policy & Social Work. Her research interests include injecting drug use, new/novel psychoactive drugs, and the implications of stigma associated with drug taking. Julie Harris is a PhD student in the School of Sociology, Social Policy & Social Work. Her doctoral thesis focuses on gender and injecting drug use, including the transitions to injecting. A second area of interest focuses on research ethics, governance, and hard-to-reach populations.

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