

# A special type of 'hard-to-reach' patient: experiences of pregnant women on methadone

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## ABSTRACT

**INTRODUCTION:** Opiate addicts in New Zealand are a heterogeneous, hard-to-reach group with illicit drug activity as their common characteristic. This project investigated the experience of a specific hard-to-reach group: pregnant women with opiate dependency, focussing on their interactions with helping services and social networks. The aim was to explore the interactions of pregnant women on methadone with helping services and social support, with the objective to make recommendations to improve service to this 'hard-to-reach' group.

**METHOD:** Questions for staff and client interview schedules were constructed, informed by a literature search. Seven methadone clinic staff were interviewed and a questionnaire was distributed to 10 antenatal clinic staff known to have previously managed pregnant women on methadone. Five methadone clients were interviewed at the clinic and interviews taped for transcription with consent.

**FINDINGS:** High risk pregnancies warrant a multidisciplinary approach, but in the hard-to-reach this ideal can itself be out of reach. Although primary care is better placed than secondary care to coordinate maternity and community support services, few opiate-dependent people have a regular general practitioner and may have perceived or actual barriers to access to care. Perceived stigma deterred these women from engaging. Women also fear that services will judge and report them, worrying about the health of their child and the powers of child protection services.

**CONCLUSION:** A fresh consideration of the functionality of services to the hard-to-reach may be beneficial. A nursing concept of 'face-work' throws some light on the misperception of well-intentioned services by the hard-to-reach.

**KEYWORDS:** Pregnancy; methadone maintenance; addiction; hard-to-reach; face-work, resilience.

## Introduction

The hard-to-reach population is very diverse and, by definition, hard to characterise,<sup>1</sup> although inequities are typically linked to low socio-demographic parameters.<sup>2</sup> This study looked at a particular type of hard-to-reach health consumer in New Zealand (NZ): pregnant women who are addicted to opiates but who choose to seek treatment for their drug use during pregnancy, taking prescribed methadone maintenance in accordance with recommended

practice guidelines.<sup>3</sup> Pregnancy is often the trigger for drug-dependent women previously unknown to medical services to seek help, presenting a window of opportunity. Prior studies, including some from NZ, have revealed attitudinal attributes toward opioid-dependent persons and injecting drug users of society in general, and of helping services in particular.<sup>4,5</sup> Helping services should periodically examine how well any hard-to-reach group is served when the window of opportunity arises.

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Methadone maintenance is recommended for opiate-dependent pregnant women. An adequate methadone dose reduces illicit drug use,<sup>6</sup> hence reducing the risk of the obstetric and foetal complications and reducing the risk of contracting blood-borne diseases during pregnancy. Detoxification or withdrawal is discouraged due to the risks associated with sudden changes in opiate intake and also the low success of maintaining abstinence.<sup>7,8</sup> Information is available on methadone pharmacokinetics<sup>9</sup> and effects on the consumer and unborn child,<sup>3</sup> but there is little information about the neuro-foetal effects of drug abuse in pregnancy. This is currently the subject of a USA research project at the National Institute on Drug Abuse.<sup>10</sup> There is also little information about psychosocial issues facing women in this situation, even though psychosocial drivers have a big impact on treatment compliance in any health setting, including pregnancy management.

Opiate users in New Zealand are a heterogeneous group, and this includes differences in their preferred opiate and method of administration. Some users exhibit primarily addictive behaviour, but others may have become habituated through the use of opioids for chronic non-malignant pain.<sup>11</sup> Opioid users may be less researched than other hard-to-reach groups, in part due to the secrecy of illicit activity. Additional psychosocial complications operate in this particular setting. Although adequate methadone replacement relieves these women from the burden of daily drug-seeking, it also isolates them from their previous social networks.<sup>12</sup> Not all will require financial services, psychiatric services, child protection or domestic violence services, but those with lower socioeconomic status (SES) and more chaotic backgrounds are less likely to engage with services, whilst the pregnancy itself can add to the chaos.<sup>13,14</sup>

Antenatal care increases favourable outcomes for both the addicted woman and child,<sup>15,16</sup> but previous fraught interactions with child protection services and health care providers are strong predictors for non-uptake of routine antenatal care.<sup>17</sup> A multidisciplinary approach with good communication between disciplines is desirable to encourage attendance and optimise outcomes,<sup>18-21</sup> but evidence confirms that this ideal

is hard to achieve. Although pregnant opiate-dependent women generally enter methadone maintenance late in pregnancy, overseas studies indicate that often they are not in antenatal care at that stage.<sup>15</sup>

Studies also indicate that misinformation abounds about the safety of methadone in pregnancy. Women may be advised to maintain minimal methadone dose during the pregnancy to minimise neonatal abstinence syndrome<sup>6</sup> and methadone in breast milk,<sup>5,20</sup> but there is insufficient evidence about the lowest dose safe from risk of neonatal abstinence.<sup>6,8,22-24</sup> The neonatal risk is attenuated by breast-feeding.<sup>3</sup> If craving is inadequately controlled, women may risk exposing the foetus to erratic additional illicit drug use. These women also face pressure from partners, friends and family to keep the methadone dose low during pregnancy.<sup>12</sup> However, pharmacology would predict that, with increases in blood volume and volume of adipose tissue in the third trimester, most pregnant woman on methadone may need to increase their dose at that stage.<sup>9</sup> In NZ, pregnant women who use opiates are ideally managed by a specialist multidisciplinary team, including the high risk obstetric team, tertiary hospital paediatricians, general practitioner and the methadone clinic,<sup>3</sup> but this is only feasible if they have a GP to whom opiate use is known, and if the women themselves comply.

Clearly some issues in the management of pregnant women on methadone are situational and specific, and some common to other hard-to-reach patients with chronic relapsing disease, but there is little information about the New Zealand situation. Rates of illicit use in NZ women are unknown, but estimates are available from population surveys;<sup>25,26</sup> the extent of IV opiate use in NZ has also been estimated.<sup>27,28</sup> Most published studies focus on hard-to-reach groups not seen in New Zealand, such as pregnant American crack cocaine users. Due to effective border control against heroin and cocaine, the NZ opiate drug scene is primarily of methadone and morphine sulphate.<sup>29</sup> In addition, New Zealand has unique ethnicity, health service organisation and policy considerations.

This was a pilot study to explore interactions of pregnant women on methadone with helping services and support. Insights were sought, from both the women themselves and service staff, about social support and access to helping services in pregnancy, with the objective to better understand service utilisation and make recommendations for reaching out to this hard-to-reach group.

## Method

Ethical approval for this project was obtained from the Central Regional Ethics Committee. The study was set in a tertiary NZ hospital methadone clinic and women's health service. The multidisciplinary methadone clinic staff included social workers, counsellors, doctors and nurses, with one nurse in the role of primary care liaison. The antenatal clinic provided all the services usually associated with a tertiary referral service. A literature search informed development of questionnaires for staff and client interviews. This search included international peer reviewed papers,<sup>6-8,13,14</sup> public government documents,<sup>2</sup> commissioned reports,<sup>30</sup> New Zealand guidelines,<sup>3</sup> policies,<sup>1</sup> protocols and academic work. A staff questionnaire was designed and piloted by two methadone clinic staff before use in semi-structured interviews by a further seven methadone clinic staff. Staff interviews were 10–30 minutes in duration, tape recorded with participant informed consent and then transcribed. The questionnaire was distributed in paper format to 10 antenatal clinic staff known to have managed pregnant women referred from the methadone clinic. The paper-based staff questionnaires were anonymous and included instructions to return them to one researcher (CC) via internal hospital mail.

Methadone clinical staff identified women from the clinic database who had been pregnant on the methadone programme since 2000. They recommended eight women suitable to approach for an interview. The criteria for recommendation was entrusted to the clinical judgement of the methadone clinic staff who knew which of these women would be amenable to an approach for research purposes and likely to keep an interview appointment if requested to. A semi-structured

## WHAT GAP THIS FILLS

**What we already know:** Studies indicate that methadone maintenance should be recommended for opiate-dependent pregnant women because it reduces the risk of the obstetric and foetal complications and the risk of contracting blood-borne diseases during pregnancy, but there is little information about the psychosocial issues facing opiate-dependent pregnant women. Studies also indicate that there is a lot of misinformation facing this hard-to-reach group.

**What this study adds:** Hard-to-reach health consumers are not a homogeneous group and the reticence of this particular hard-to-reach group to engage arises in part from their perceptions of adverse attitudinal attributes from helping services. Services should consider face-work and the implications of resilience in their patient–professional interactions, as these factors may influence help-seeking behaviour of the hard-to reach.

patient interview schedule was formulated using themes from both the literature search and staff interviews and questionnaires. Patient interviews were held at the clinic premises, with an option for a female health professional or other support person to also attend. All patient interviews were conducted by one medical researcher (CC) who was not involved in the clinical management. Patient interviews were also taped for transcription with consent.

Analysis of the quantitative data was thematic, in keeping with grounded theory. Themes from the staff interviews informed an ordered analysis of the patient interviews.

## Findings

### 1. Staff interview and questionnaires

All seven methadone clinic staff invited to participate for interview did so, indicating high interest in the topic. These methadone clinic staff participants were a semi-purposeful mix of case managers, nurses and prescribing doctors. In contrast, the high caseloads and rostered shifts precluded personal interviews with antenatal staff, and only four of the 10 antenatal clinic staff returned their questionnaires, despite reminders. The invited antenatal staff had included midwives, nurse-midwives and nurse-managers.

All responding staff acknowledged pregnancy as a window of opportunity when otherwise hard-to-reach women may be more forthcoming and motivated to engage with the service:

During pregnancy women tend to have a heightened sense of responsibility... (Methadone clinic doctor).

The discourse from staff at both the addiction and antenatal services provided examples of distancing 'us', the health service, from 'them', the pregnant women, not reflecting the ideal model of multidisciplinary patient-focussed care, but rather a 'you/us' vs 'them' mentality, and disrespectful of patient autonomy and distrustful of patient motive:

You don't want them to go there [to another health service] and not disclose their methadone treatment and have them say 'I'm not sleeping' have them [other services] prescribe benzodiazepines. (Methadone case manager)

In particular, antenatal clinic staff commented that pregnant women on methadone take more time than their average patient, are less receptive, and exhibit 'lack of compliance' and 'frequent missing of appointments'. Despite these comments, most staff recognised that pregnancy can motivate women to control drug use, driven by fear of harm to the foetus. Staff observed that concern for the unborn child's welfare may even cause women to resist recommended methadone dose increases:

Even though they are having withdrawals they don't want to increase... Their concern is that they want their baby to be born as healthy as possible with as little opioid dependence as possible. (Methadone clinic nurse)

However, if an unplanned pregnancy occurred when drug use was not clinically stable, staff experience was that the pregnancy simply contributed to existing chaos in that woman's life. Clinical staff stated that some of these women come from very dysfunctional family backgrounds, do not have basic life skills, and require coaching about regular meals and good diet.

From the perspective of service staff, adequate family support is often lacking and it is difficult

to encourage family engagement. Some women don't seem to want to involve their families, perhaps due to longstanding family dysfunction. Consequently some families may first confront two realities at once; the addiction and the pregnancy. The experience of methadone staff is that some family members may react angrily, challenging the need for continuing drug use (methadone) during pregnancy:

They're (the client's family) usually too angry to be receptive in those cases. ...eventually they come around when they see the benefits. (Methadone clinic nurse)

Others reported that women may also want the pregnancy to be kept secret from helping professionals, such as their GP. There are considerable possible hazards for a pregnant woman who has not already disclosed to her GP that she is on methadone, but some patients do not have a GP at all. Methadone clinic review alone is considered suboptimal, especially if that is the only opportunity for regular medical and antenatal review. Specialist services then feel obliged to step in to deliver primary care, although it is not their role:

...alerted to the fact that they are pregnant quite early on we'd endeavor to see them obviously more than three monthly. (Methadone clinic doctor)

In the experience of these staff, patient reticence also has repercussions for appropriate referral on to other services. The fear of losing the infant to child protection agencies is a very common underlying reason:

We would want to refer them as quickly as possible and get them engaged with High Risk clinic. And sometimes that's quite difficult, especially if they've had children taken off them before because they're very reluctant. They don't want us to inform anybody that they're pregnant. (Methadone clinic nurse).

Knowing that, clinic staff actively seek to help the women to manage that risk:

I've worked out a plan of things this person needs to do in order to have their baby with them when it's delivered...they have to have stable housing

and we have to be sure that they're not injecting, and there's a whole host of things that CYFs will require... (Methadone clinic nurse).

Staff suggested that reticence to engage with helping services may also arise from the compounding effect of pregnancy and dependence on daily methadone on already low self esteem:

There is a stigma about it. They've been judged. They've been looked down upon. (Methadone case manager)

There was also an acknowledgement that improved inter-service liaison could reduce on-referrals and enhance interdisciplinary care. However, pressures of staff shortages and staff turnover were also mentioned as barriers to integrated care across services and within services, with recognition that these staffing factors also hampered the development of, and continuing rapport with, individual women.

## 2. Patient interviews

Staff identified, through clinical record audit, women from a total methadone clinic list (then) of 300. Nineteen women had had pregnancies managed on methadone since 2000; 17 of these women had remained with the methadone service after delivery. Eight women were recommended for approach for this pilot, six agreed to in-depth interviews. Time permitted only five interviews, as some were rescheduled. None of these women were pregnant at the time of interview. Age and ethnicity are withheld to preserve confidentiality of such a small sample. Three women had also been on a methadone programme during prior pregnancies. Although not a focus of this study, clinical records that were reviewed during audit revealed that neither the antenatal clinic nor the methadone clinic held full information about the drug use, pregnancy history, occupation and social history.

The women confirmed self-judgment and low self-worth:

It's just me who does this to myself. I choose to use and so I always feel like I deserve to be looked down upon by these doctors and nurses.

The women also provided many examples of perceived hopeless dilemmas between knowing what was right, but doing something else:

This overwhelming feeling that I had of guilt... I was just torn two ways by this really strong desire to just stick a... needle in my arm and the feeling of what is that doing to my baby.

All I was worried about was me smoking pot and what if she'd (baby) be alright but I knew then I shouldn't be smoking pot, but I couldn't deal with being sick.

Even though these women had been managed on methadone maintenance during their pregnancies, opiates were not necessarily their drug of choice; four women preferred methamphetamine, and cannabis and benzodiazepines were commonly mentioned. There was clear ambivalence about being on methadone, especially arising from the woman's own community, and an acknowledgement by some that this ambivalence had contributed to late presentation:

I was really anti-methadone. Amongst the junkie community who aren't on methadone they say 'Don't get on methadone, you'll be on it for life.'

The worry about drug exposure of their baby had led some of these women to consider abortion:

...didn't want to have the baby 'cause of the heroin and 'cause I've been using methadone for about a year plus benzos and things like that.

These women had become acutely aware that use of their drug of choice was no longer just about themselves:

Really hard to live with myself if I knew my baby had withdrawals. I was really vulnerable at that stage.

Judging by comments of these women, the health services seemed to be giving pregnant women mixed messages about tobacco smoking and also continuing with illicit drug use such as marijuana. One woman reported a drug clinic staff member as saying 'Look you've got enough to deal with, with trying to get a drug problem under control don't take on too much at once or you'll set

yourself up for a fall.' But, in contrast, the public messages about alcohol had been taken seriously:

I didn't drink during my pregnancy because of fetal alcohol syndrome.

Those women who were engaged with helping services had experienced stigma in many forms from many quarters:

I never ever went to the chemist without my partner when I was pregnant 'cause I couldn't cope with the snide comments.

The way I'm treated by people is intolerable. It's here (the clinic), it's the chemists, the doctors, society, (the) job, going for jobs. Going back to my previous career is just about impossible.

My doctor, he didn't want to know me. He just...put me to the high risk people. He didn't...want to have anything to do with it, with the methadone and that.

There were poignant stories of battles with health services, where women felt the need to hide the fact of their methadone maintenance as they perceived they were treated differently.

I don't have a criminal record. But... the key thing is that understanding that people do things out of desperation not out of choice.

Communication suffered and also the sense of being understood. The following comment referred to the high-risk antenatal service:

Obviously they see so many women... that they're just kinda immune to it...You can't have any kinda talk... it's all very medical.

Addiction issues also complicate relationships with family members at a time when that support would be most helpful:

I was too scared to tell my mother. Nothing's ever good enough for her. And especially since I've done so many stupid things in my life. She's real bummed out on me.

My in-laws don't still don't speak to me. They blame me for my...partner's addiction. And they

hate me basically. I let them see their grandkids... for them to have a relationship...with my children they need to have not a relationship but at least a civil standing with me.

Some families come around sooner or later, but reluctantly:

I'll tell you how long it took. It took a year, a whole year, before we were even allowed down to my mum and dad's place.

Friendships also suffered because the pregnancy had resulted in these women having less contact with prior associates, some reported being 'eliminated' by peers as a result of the perceived stigma of being pregnant and/or on help from health services:

I had all these friends who were like alcoholic, drug addicted...it was cool they were good but it got with those girls you couldn't really...trust them either.

The women realise that they actually have few friends:

The ones that we did have in the last couple of years have invariably been drug acquaintances rather than proper friends. So as soon as we got on the programme it was something we (thought) 'well we (will) try to just leave all those acquaintances behind' and we did so again we became quite insular.

This makes these women feel that they were unsupported in pregnancy and treated differently:

There was no one person who co-ordinated the whole thing, it was me.

## Discussion

To our knowledge this study is the first in New Zealand regarding pregnant women on methadone as a hard-to-reach group that explores the experiences of the women themselves in their interactions with health and social networks. It was a small pilot study but its strength lies in the rich narrative, particularly from the women's interviews.

Many writers recommend a multidisciplinary multi-agency approach to the care of high risk



pregnant women,<sup>13,15,17,19,20</sup> but this project has shown that actual practice lies far from this ideal. Primary care has theoretical advantages in coordinating pregnancy care, being community-based and multidisciplinary, often with the services all under one roof, but few opiate-dependent people have a regular GP. These women also had perceived or actual barriers to access to primary care, including the difficulties of communication, feeling not understood, and a sense of stigma from helping services. Some had not previously told their GP about their addiction. This is consistent with recent research that shows that GPs and their patients do not always make use of opportunities to discuss addiction, a sensitive topic that is fraught with communication difficulties.<sup>31</sup>

One important finding, relevant to all levels of health care provider including primary care, was that women in this situation especially worry about having their child uplifted, particularly when previous children have been uplifted.<sup>17</sup> Services may face a trust dilemma in knowing of the patient's concern, but needing to notify authorities if they are concerned that a woman is not capable of looking after the child. Suboptimal outcomes become self-reinforcing.<sup>17,32</sup>

These women had also reported inconsistent information about their condition and its management: dose safety, neonatal withdrawal, and breast-feeding. This results in women becoming confused, fearful of the outcome and even more distrustful of services.<sup>15</sup>

Personal perception of stigma was one factor that had a major impact on the engagement of these women with helping services during their pregnancy. The perceived stigma came from surprising quarters: partners, family and friends, as well as health professionals.<sup>17</sup> This influenced the woman's choice, not only to limit engagement with health and helping services, but also her interactions with prior social support, friends and family. Overseas studies have confirmed that stigma, real or perceived, contributes to delayed presentation to both antenatal and opioid services.<sup>33,34</sup> Drug-using women experience feelings of guilt, anxiety and fear concerning their drug use when pregnant<sup>18-21</sup> and pregnant women with an addiction believe that helping

professionals will view them as irresponsible or inadequate. That belief may be entirely unfounded, but it arises from formative past experiences; conditioning not only sensitises these women to interpret well-meaning interactions as stigma, but untoward interactions also exacerbate guilt and compound any pre-existing mental health afflictions.<sup>14,20</sup> The well-meaning approach may be met with an unexpected response, making the interaction even less comfortable for all concerned.<sup>14,19,20</sup>

The dialogue of both the women and health professionals provided clues to the source of the women's perception of service-related stigma: frustrations over missed and rescheduled appointments; pressured appointments lacking time to

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establish trust; staff turnover; staff shortages; conflicting information and the personal distance kept by some staff, with a 'them-versus-us' mentality apparent in some comments. This left the women feeling abandoned by the helping services, despite the psychological defences that they, the hard-to-reach, had themselves already overcome in order to reach out. It is acknowledged that these perceptions arose in the specialist antenatal and methadone clinic setting as these women did not have a GP. However, it behoves all services to consider if there is actual stigma arising from the attitudes and beliefs of some health professionals. The impact of staff turnover, appointment pressure and access to accurate information affects all patients, but especially the hard-to-reach, and that compounded the patient perception of abandonment. Perceived stigma is attitudinal, rather than actively discriminatory, so it behoves all services delivering to marginalised groups to consider the possibility and implications of perceived stigma as a barrier to the hard-to-reach.

It is helpful to explore reasons why a helping service and a patient reaching out for help might not only miss each other's good intentions, but also misinterpret the interaction. Nursing literature refers to the very useful concept of face-work which, although found throughout the social sciences literature, has not filtered through into medical practice. In health settings the importance of face-work has been much studied in the interactions between nurses and patients, as in the examples of J Spiers.<sup>35</sup> All such interactions, including GP-patient medical consultations, are 'saturated with face-work'.<sup>36</sup> Politeness theory uses this concept to explain the complexity of social interaction. Interactions may show giving of face, saving face and taking at face value. Face-work is 'a means of understanding the context of interaction and the ways in which a nurse and client choose speech patterns based

medical advice), power differential/awareness of self-competency (the service is too busy for me/ the doctor knows best) and perceived criticism (implication that patient had not been doing all the right things). This concept is also particularly relevant to cross-cultural communication. In the interactions between our participants and their health professionals, the described face threats had left these women with an impression of attitudinal stigma.

Cost and accessibility, often cited as barriers for the hard-to-reach, may not have been key barriers to engagement here. These services were free, provided community outreach (methadone and domiciliary midwifery), and could even arrange transport (hospital antenatal clinic). This raises the possibility that the hard-to-reach perceive those face threats that are intrinsic to health service provision differently to others, or alternately may lack the resilience to overcome them. In health services the balance of face-work usually lies in favour of the health professional, who controls what is and is not discussed in a consultation. Thus face-work may be a factor contributing to other groupings of hard-to-reach, throwing light on the difficulties that services face even when they try to reach out. It raises a challenging question: in health interactions, must the balance of face-work always fall in favour of the health professional?

In exploring the interactions of pregnant women on methadone, this pilot study has exposed perceptions patients have of themselves and of helping services and the impact of these on support utilisation. Already this has triggered two further projects: a subsequent project, entitled 'NZ Families Living with Addiction', looked more closely at the concept of resilience within families living with addiction. This has just reported to the funder, the Families Commission, and will be publicly available shortly. Another project, about to commence, will investigate interactions when both partners in a relationship are also in treatment.

This project also set out to make recommendations for reaching out to this hard-to-reach group. It has raised some obvious messages to improve services to this, and other hard-to-reach client groups: good team and interdisciplinary commu-

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on perceptions of face needs, face threats, and contextual features of power, culture and social distance'.<sup>37</sup> Time has not diminished the usefulness of this concept, first proposed in 1976. Face needs are 'one's simultaneous need to maintain autonomy as well as one's need to be liked or to feel competent or wanted'.<sup>37</sup> The consulting health professional and the patient (pregnant woman, in this instance) both juggle these conflicting face needs during any interaction. The communication strategy of each will naturally be to protect their own face needs, but in doing so this may produce threats to the face needs of the other party. Politeness is, of course, very important to health professional roles, but may conflict with the drive to comprehensively assess and give evidence-based health advice; this is a complex interaction where face-work generally favours the health professional. Inadvertently all patients receive face threats in the form of personal space imposition (examination, blood and urine tests), personal information requests (history taking), held health beliefs challenged (health education/



nication; enquiry into fears of patients in order to address these; awareness of the possibility of actual or perceived stigma and willingness to address that; awareness of the presence and implications of face-work in clinical interactions, and use of face-work to facilitate engagement in the best interests of the patient. The planned research may also provide additional insights into service provision for other hard-to-reach.

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## COMPETING INTERESTS

None declared.