



Claire Hooks

*challenges the stereotyped view of drug using pregnant women and explains how midwives can support these clients in managing their childbirth experience*

# Paranoid or persecuted? The stigmatisation of pregnant drug users: a literature review

**SUMMARY:** Substance misuse is a complex issue, fraught with many challenges and inequalities for those affected; most of these are as a result not of the substances themselves, but of the underlying web of socioeconomic problems associated. Whilst the literature suggests that pregnancy may be a 'window of opportunity' for substance misusing women, it also suggests that there are several barriers to women engaging with health care. One of these is the fear of being judged and stigmatised by healthcare professionals. This literature review looks at research in the field of substance misuse in pregnancy, focusing on the 'stigmatisation' of pregnant drug users by healthcare professionals, illustrating the potential impact of this upon care.

**Keywords** Substance misuse, stigma, midwives, attitude, engagement

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### Introduction

It is estimated that around 5 per cent of all births in the UK are to women using illicit substances (Crome and Kumar 2007). However, it is difficult to estimate this figure accurately for numerous reasons, partly prompted by an unsurprising reluctance to reveal this information, including: feelings of shame, denial and stigma experienced by the user; lack of awareness and knowledge among professionals in antenatal services; the presence of co-morbid psychiatric disorders (such as depression and schizophrenia); and socio-cultural barriers (gender, deprivation, education) that may prevent assessment being carried out appropriately. Consequently, there is a paucity of research in this field and much of what exists is outdated. However, it is known

that about one third of drug users in treatment in the UK are female and 61 per cent of these are mothers (National Treatment Agency for substance misuse (NTA) 2012).

In this review, the terms substance use/misuse and drug use/abuse will be interchanged and are intended to refer to the use of illicit substances only.

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### Practice challenge

Take a moment to consider your own view of drug use and your knowledge of why people engage in it. How does drug use make you feel? How do you feel about pregnant women using drugs?

## Stigma

The Australian Injecting and Illicit Drug Users League (AIVL) (2011: 46) report, *Why shouldn't I discriminate against all of them?* states that:

*'Attitudes towards injecting drug users are negative, entrenched and generally unhelpful. They leave the general population living in fear of a subset of the community they really have no need to be afraid of, and the people they are stigmatising and discriminating against are left with reduced access to health care, housing, employment and other social needs. This must inevitably be a net loss to society.'*

Similarly a UK survey (United Kingdom Drug Policy Commission (UKDPC) 2010: 9), reported that drug-using parents were subject to condemnatory remarks in the media almost as frequently as offenders, where adjectives were used such as 'vile', 'hopeless', 'dirty', 'squalid', 'evil' (UKDPC 2010: 9), 'tainted, blemished and polluted' (McLaughlin and Long 1996: 284). Furthermore, DeVille and Kopelman (1998) suggest that women who are known to be users of illicit drugs, experience public scrutiny during pregnancy, particularly increased criticism of their parenting capacity: there is the linked perception that illicit drug users are of weak personality and in some way corrupt and flawed (Norman 2001). This idea feeds the notion that drug users are violent, manipulative and engage in criminal activity.

### Stereotypes

For some substance misusing women, pregnancy can be seen as an opportunity to make changes, as discussed later, but others do not feel able to attend for care, potentially putting themselves and their unborn baby at risk (See *Table 1*). In addition, Taplin and Mattick (2011) reported that women who

Table 1 Effects of substance misuse

<b>Physical effects</b>	Blood-borne viruses such as hepatitis or HIV, contraction of sexually transmitted infections, overdose, anaemia and poor diet, various mental health problems and accidental and non-accidental injuries (Prentice 2010; Leggate 2008).
<b>Psychological effects</b>	A life dominated by drugs - with drug taking becoming a priority - anxiety, unpredictable behaviour and irritability, sleep problems, paranoia, depression, stress and memory lapses (Prentice 2010).
<b>Social and interpersonal effects</b>	Family break-up, unreliability, poverty, a need to engage in crime/prostitution to pay for drugs, becoming a victim/perpetrator of physical/sexual/psychological abuse, loss of employment, being evicted or homeless, social exclusion/isolation and frequently associations with persistent offenders (Prentice 2010).
<b>Financial effects</b>	Constant requirement to find money to buy drugs, leading to debt and an inability to pay for basic needs (Prentice 2010).
<b>Legal effects</b>	Arrests, warrants/fines and probation orders, all making employment chances much more difficult and increasing stigma (Prentice 2010).
<b>Pregnancy specific effects</b>	Poorer maternal and fetal outcomes compared with their non-using counterparts, including: miscarriage, pre-term birth, intrauterine fetal death, placental insufficiency, eclampsia, septic thrombophlebitis, postpartum haemorrhage, fetal distress, low birth weight and fetal malformations (Corse and Smith 1998).
<b>Additional effects on fetus/baby</b>	Risk of mother-to-baby transmission of blood-borne infections, poor growth, sudden infant death, stillbirth and neonatal abstinence syndrome (Drugscope 2005).

misused substances were disadvantaged, tended to be single, had little formal education, were frequently on benefits, experienced financial problems and were often living in social housing. A significant number also had mental health problems, associations with crime and had experienced some type of

physical or sexual abuse as a child. Whilst this is an Australian study, it reflects a similar profile in the UK (Adams 2008).

### Fear of being judged

Almost without fail the primary cause of women not attending is stigma, perpetuated both by general society and professionals, including midwives. Studies conducted by Klee et al (2002) and O'Reilly et al (2005), regarding pregnant substance misusing women's views and experiences of services reiterate this, highlighting from the perspective of the substance user, that one of the barriers to accessing care was fear of staff attitudes and of being judged or treated differently or unfairly. Describing their negative experiences and how they try to hide their drug user status >>

*For some substance misusing women, pregnancy can be seen as an opportunity to make changes*

at all costs, often to the extent of avoiding treatment are these women:

*'I was looked down upon as the scum of the earth'*

(cited in Lloyd 2010: 42)

*'They were actually being different to her than to the other patients ...'*

(Radcliffe 2011: 5)

*'I wasn't very sure ...I thought maybe I would be labelled a junkie. You know you wouldn't be treated the same...'*

(Hall and van Teijlingen 2006: 5)

### The cost of alienation

Hepburn (2004) adds that this is compounded by the fact that women who use illicit drugs are often alienated socially and, in addition, have less support financially, from social care and health care as they often don't engage in treatment. This is related to the women's fear of legal consequences and also of having their children removed (Adams 2008; Hepburn 2004);

*'I was just too frightened, too scared, thinking they were going to get me into trouble and take her off me the minute she was born.'*

(Hall and van Teijlingen 2006: 5)

This fear of being seen as irresponsible or inadequate carers often results in poor self-esteem, guilt, depression and then ultimately,

### Practice challenge

Do these views resonate with you, or your practice? Do you feel your knowledge in the area of management of substance misuse in pregnancy is good?

denial of drug use (Klee et al 2002) and this consequently compounds the attitudes and labels attached to using.

### Pregnancy as a motivator for change

It is suggested that for drug-using women, pregnancy can be a significant motivator for change, driving them to seek treatment for their drug problem. In her UK based study, Radcliffe (2010) reported that many women described how they kept their drug use secret from people they knew and pregnancy was sometimes the first time that they acknowledged their drug use to health professionals.

This has been reiterated in other studies, where women have reported that pregnancy was their impetus to change (Hall and van Teijlingen 2006: 8):

*'I just thought I felt I couldn't do that to an unborn child that is so innocent; you're actually giving that baby a habit.'*

In addition, the women in this study showed great determination not to return to their drug use:

*'It dawned on me when he was born: I thought all I have to do is not use. The whole future depends on me not anyone else'* (Hall and van Teijlingen 2006: 8).

### Midwives' views

Klee et al (2002) suggest that midwives engaging with substance-misusing women is the key to enabling change to occur and that they are in an optimum position to do so. A pregnant woman attending antenatal care enables midwives to facilitate and promote good health, through education, prevention and intervention.

All the same, much of the research doesn't reflect this. McLaughlin and Long (1996) found that the majority of nurses interviewed felt

that drug users constituted a threat to society, perpetuating and reflecting the fear beliefs that society holds. In reality, whilst there is a link to crime with substance misuse, this is small and it is acquisitive, not violent crime (AIVL 2011).

In addition, Lee et al (2010) interviewed 15 midwives, who reported that they lacked time, resources and knowledge and thus didn't feel confident discussing drug use. Furthermore, the midwives made assumptions relating to the background of users of illicit drugs, thus reinforcing the concept of stereotyping and stigma. They suggested, for example, that white/middle class clients know not to take drugs during pregnancy and in addition those who are taking drugs are often already identified or involved with other agencies: *'I think the majority of people who I've ever met who are taking drugs or have a drug problem are already seeking help for their drug problem.'*

They also suggested that their knowledge of referral processes was lacking, with some midwives stating that they would only offer a referral if it was appropriate or necessary.

Raeside's research (2003) found that the views of health staff were, in the main,

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negative toward substance misusing women. Whilst a study by Jenkins (2013) concluded that, on the whole, the midwives demonstrated positive attitudes toward substance users, there was some discrepancy between concurrent sentiments, such that it also found that fewer than half of the midwives questioned felt sympathetic toward pregnant drug users.

These beliefs from both society and health care professionals regarding threat and parenting capacity are not founded on evidence from the drugs field. Evidence has shown that parental substance misuse can be associated with higher rates of child maltreatment, but substance use itself does not necessarily mean that parents are abusing or neglecting their children. In addition, research from overseas has also found that families in which alcohol or other drug use is present are 'more likely to come to the attention of child protection services, more

likely to be re-reported, more likely to have children removed from their care, and more likely to have them remain in care for long periods of time, than are families with the same characteristics but no substance use' (Taplin and Mattick 2011: 8), confirming the prejudice and stigma perceived by users.

### Place of the midwife

In studies women speak affectionately regarding individual health care staff that have shown real interest (O'Reilly et al 2005; Hall and van Teijlingen 2006); amongst the most highly valued aspects of care were non-judgemental attitudes of staff.

A retrospective audit of services for substance misusing pregnant women by Leggate (2008), found that, although the women's lives were often complicated by social problems, women who were well supported and felt they developed a relationship with an individual health carer, such as the drug liaison midwife (with specialist knowledge in the area), were more successful in achieving stability and improved health outcomes for both themselves and their infants than those who were not. They reported that they developed a relationship over time with their midwife, and during this time their motivation to change and comply with treatment also improved.

Non-punitive, non-judgemental, nurturing and supportive care was found to be most useful in forming a good and effective relationship with substance-abusing or recovering women. The women receiving this type of care were more likely to voluntarily admit to substance use/abuse or relapse, thereby facilitating the midwife to provide appropriate care (Corse and Smith 1998).

### Final thoughts

An alternative view to that of stigma or

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persecution on the part of the health carer is that of paranoia in the user (the user's perception). It is my view that paranoia, which can be associated with substance use, may sometimes be the cause of social isolation; however, there is also clear evidence that stigmatisation is real, does exist and that it can have a significant detrimental effect on this group of women and their families. The ability to apportion blame and ascertain cause and effect in relation to this dichotomy (paranoia vs persecution), however, is impossible to accurately determine. It is certainly an area that warrants further research. After all, it is likely to have an impact on the effectiveness of interventions designed to change attitudes and thus reduce stigmatisation; that is to say, if the issue is one of paranoia and not so much about persecution, tackling the perceived

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### Practice challenge

Where do you feel your views around substance use come from? Personal or professional experience? Society? Fear? Lack of knowledge?

### Final practice challenge

Take a moment to reflect on how reading this has made you feel about your management of pregnant drug users. What will you take away and incorporate into your own practice?


perpetrators will likely have little effect.

## Conclusion

Health professionals are just as affected by societal norms as they are influenced by their own backgrounds and indeed their midwifery education. Beliefs and attitudes are difficult to change, especially when they are longstanding seen as going against the grain of dominating practice and beliefs in the community.

It is clear from the review that although the voice of the women has been heard to some degree, there is a real lack of research based in the UK, both in terms of the way in which 'general' midwives 'frame' substance misusing women (as discussed above) and also regarding the effectiveness of educational intervention, in terms both of changing midwives' attitudes and of improving engagement and experience of maternity care by substance users. Given, however, that education is empowerment, it stands to reason that improving education is a positive move in improving attitudes, reducing stigmatisation and increasing engagement; hence the subject of the author's doctorate looking at the effects of specialist education

*Non-punitive, non-judgemental, nurturing and supportive care was found to be most effective in forming a good and effective relationship with substance abusing or recovering women*

upon attitudes toward substance misusing pregnant women... Watch this space! 

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