

# Understanding barriers to sexual health service access among substance-misusing women on the South East coast of England

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## ABSTRACT

**Objectives** Evidence suggests substance-misusing women (SMW) experience disproportionate sexual health morbidity and poor uptake of interventions including contraception and cervical screening, yet there has been little investigation of sexual health service access issues for this population.

**Methods** Twenty women with problem drug use in Hastings in South East England, UK participated in a one-to-one interview with a researcher to explore experiences and beliefs surrounding access to a range of sexual health service interventions. Transcripts were open-coded and themes were elicited and organised concerning barriers to access.

**Results** Drug-use lifestyles, trauma and low self-worth framed the lives of SMW and hindered sexual health service access through: depleted practical and emotional resources to enable attendance; high perceived emotional cost of discussing sexual histories, and coping with tests and unfavourable results; and low anticipated value of sexual health interventions due to low perception and minimisation of risk and perceived incompatibility between drug use and sexual well-being.

**Conclusions** A range of practical, social and emotional barriers to sexual health service access exist for this population, presenting a context from within which use of services may come at considerable personal cost to SMW. Interventions addressing anticipated stigma and emotional, hygiene and fiscal concerns are warranted for this population.

## INTRODUCTION

England's National Strategy for Sexual Health and HIV<sup>1</sup> had a requirement to improve sexual health service access that led to delivery innovations<sup>2</sup> for target

## Key message points

- ▶ Anticipated drug-use stigma, sexual history taking, undergoing tests, and coping with results presented discrete emotional concerns for substance-misusing women (SMW).
- ▶ Non-access was understood as an act at times self-protective of drug-use recovery, emotional well-being and avoidance coping strategies.
- ▶ Social, emotional and fiscal support is likely to be instrumental in enabling SMW to access sexual health services.

populations such as sex workers (out-reach services) and intravenous drug users (IDUs) (provision of blood-borne virus testing in substance misuse services). General health assessment guidance from the National Treatment Agency for Substance Misuse includes sexually transmitted infection (STI) risk assessment (either directly or by referral) but excludes assessment of pregnancy risk.<sup>3</sup> The evidence base however suggests that a range of sexual health risks and morbidities are experienced not only by female injecting drug users (IDUs) but by substance-misusing women (SMW) as a whole (substance misuse in this context incorporating studies of female populations using variously crack cocaine, opioids and 'illicit substances'). Studies indicate high risk of STIs,<sup>4 5</sup> and of unintended pregnancy<sup>6</sup>; and elevated sexual health risks including sexual assault, intimate partner violence and exchange of sex.<sup>7–9</sup> Infrequent cervical screening<sup>10 11</sup> and inconsistent condom and contraceptive use<sup>3 7</sup> further suggest services have not been successfully provided

to SMW. Despite this evidence base and guidance, no contemporary qualitative research has sought to understand sexual health service access for SMW, excepting a study of barriers to ante- and postnatal care among Scottish SMW,<sup>12</sup> which found fear of encountering drug-use stigma and of removal of children predominated. Similarly, research investigating SMW's access to drug treatment services has identified barriers concerning: fear of stigma, fear of removal of offspring from their care, and the male-oriented structure of services.<sup>13</sup> This literature is part of a broader body of evidence concerning gender differences among substance-misusing populations. In particular women are more likely than men to be introduced to drug use by a romantic partner,<sup>14</sup> and to experience severe drug dependency<sup>15 16</sup> and psychiatric comorbidity.<sup>17</sup>

This article reports on a qualitative interview sub-study, which (together with a survey of sexual health risks, morbidity and service engagement) formed a mixed-methods study funded by the National Institute for Health with the dual aims of understanding and quantifying sexual health needs and service use among SMW, and specifying a model for sexual health service delivery for this population.

The aim of this sub-study – to identify and understand barriers to sexual health service access – was operationalised by identification and understanding of the following:

- ▶ Risks and opportunities surrounding sexual health
- ▶ Barriers to, and facilitators of, sexual health screening, cervical screening, use of family planning services, and contraception use
- ▶ Women's perceptions of their need and desire for sexual health and family planning services
- ▶ Current general usage of statutory and non-statutory health care services.

'Barriers' in the context of this research are defined as all factors that may prevent, hinder or discourage use of services; and 'access' as all aspects of service engagement including attendance at premises delivering sexual health services, interaction with staff and uptake of interventions.

## METHODS

A qualitative, interpretivist approach was adopted, such that engagement and non-engagement with services by SMW were explored as social, contextual and meaningful acts. A convenience sample was recruited from women, aged 18+ years, and living in the Hastings and Rother area on England's South Coast, who had completed a survey of sexual health risks, morbidity and service engagement and who self-identified as having a substance-misuse problem and had used one or more of the following substances within the previous month: heroin, crack, methadone (prescribed or illicit), cocaine (powder), ecstasy, amphetamine, Subutex<sup>®</sup> (prescribed or illicit),

Suboxone<sup>®</sup> (prescribed or illicit), cannabis or benzodiazepines. Among this sample the mean age was 36 years, 51% had a self-defined 'substance-misuse problem' of more than 10 years' duration, 25% reported hazardous drinking; and in the previous month 43% had injected drugs, 67% had used heroin, 57% had used crack and 81% had used methadone. Those interested in participating provided a name and telephone number to researchers at survey completion sites, which were a drug treatment service and a drop-in for insecurely housed and vulnerable people.

Sixty-seven women were contacted sequentially by a researcher until the target of 20 interviews had taken place. Thirty-five women did not answer their telephone, two cancelled interviews, nine failed to attend, and one interview was abandoned due to ill-health.

Interviews took place at survey completion sites. Immediately prior to interview, participant understanding of the study, capacity to consent and emotional well-being was assessed and participants invited to sign a consent form. Interviews were conducted by a female researcher trained to provide immediate emotional support. Participants who became distressed were asked if they wished to discontinue the interview. Participants were offered care co-ordinator or researcher support immediately post-interview and a list of counselling services. A £10 shopping voucher and reimbursement of childcare and travel costs were provided.

Each participant undertook a one-to-one unstructured interview conducted using a topic guide developed with service user researchers. Topics comprised experiences, personal need and perception of: contraceptive advice and supply, cervical screening, STI/HIV/hepatitis screening and treatment, and antenatal and abortion care. Interviews followed the principles of 'conversations with a purpose'.<sup>18</sup> To establish rapport and contextualise sexual health care access participants were asked firstly to describe their substance-misuse history. Relationship and fertility histories were also explored to contextualise and bring forth sexual health care experiences, thus acting as a data collection aid in eliciting respondents' experiences. [NB. It is important to stress that neither interpretative analysis within narratives nor a broader narrative methodology were used.]

Interviews were audio-recorded, anonymised and transcribed. Transcripts were open-coded in NVIVO8, and these codes used to inductively develop semantic and interpretative themes, and then meta-themes, which were pertinent to the research question.

## RESULTS

Low self-regard, traumatic experiences, and drug use and its associated lifestyle emerged as mutually-sustaining factors that dominated the daily lives of participants. These factors acted (and interacted) to generate a number of barriers to sexual health care

access, which clustered into the following ‘meta-barriers’: (1) lack of resources to support attendance at services, (2) anticipated high emotional cost of accessing services and (3) low perceived value of undergoing interventions. Each of these meta-barriers is considered in turn.

#### Lack of resources to support attendance at services

First, drug use, and its attendant lifestyle, depleted the resources that women needed to enable physical attendance at services. Hence lack of available monies and washing facilities, and the subsuming nature of the daily cycle of acquiring, taking and withdrawing from drugs, acted as both practical and emotional barriers to attendance.

*“...the only time I can say that when I went to appointments, why I went is, ‘cause I’d had my drugs and I’d actually got some money in my pocket ... that wasn’t needed to be spent on drugs”*

*“...you’re either chasing the drugs, trying to get money for drugs and drink ... by the time you get home you’re drunk anyway, or off your head ... in the morning you wake up, you’re ill so you gotta go out and get something ... so you don’t get round to doing that sort of thing ...”*

Personal hygiene concerns arose in relation to heavy drug use and inadequate access to washing facilities as a consequence of insecure housing.

*“I don’t wanna go ... in front of a strange woman ... not having been able to have even had a wash ...”*

*“... I nearly didn’t want to [have a Hep C test] ‘cos ... I knew that when I took my jacket off, the whole place would stink”*

#### Anticipated high emotional cost of accessing services

The high ‘emotional cost’ to women of undergoing sexual health interventions was a significant barrier arising from low self-regard, traumatic experiences and drug use-related stigma.

Previous experiences of drug-use stigma by service providers, internalised drug-use stigma, and lack of self-regard and attendant lack of self-care acted as barriers by reducing participants’ willingness to care for themselves in all aspects of their health care, and by generating anticipation of stigmatised responses from others.

*“If I’m using drugs then I’m ... at a real low, I don’t give a s\*\*\* about myself”*

*“I keep getting letters [about cervical screening] ... and I keep getting letters about ... my epilepsy ... but I don’t ever go.”*

*“Who wants to bother with some helpless alcoholic bloody drug abuser, kind of thing?”*

*“... when I had to go [to the GP] ... they tap on the thing and it all come up ... and you can see their ... face change you know”*

Three discrete aspects of intervention – undergoing tests, coping with unfavourable results and discussion of sexual and reproductive history – each represented a significant emotional concern to some participants. Sexual history taking was understood to be feared as a stigmatising experience and as a disruption to the coping mechanism of not discussing traumatic experiences and stigmatised behaviours. Some participants were acutely aware of the requirement to discuss their histories.

*“I don’t wanna talk about what I did in the past. And you have to if you’re gonna go and have ... anything to do with sexual health and then you have to say ‘ell I was a prostitute’ or ‘I was this”*

Equally, within the research interview itself, participants gave strong verbal and non-verbal cues of their reluctance to discuss the impact of sex work, looked-after children and assault on their sexual health service access. In particular, many participants reported incidences of sexual violence from partners and others, which they coped with by not thinking about or discussing the event.

*“If it’s not brought up it didn’t happen to me, that’s the way I sort of look at it ... you know, just blank it right out”*

Fear of undergoing tests and coping with unfavourable results were also raised by interviewees. Some participants who had undergone intimate testing procedures reported the experience as painful and frightening, one participant having obtained diazepam to enable her to attend a cervical screen while another experienced an invasion of privacy from testing.

*“I don’t like blood tests at all ... I don’t even like doing pregnancy tests ... especially at the doctors when you have to take it out into the waiting room to give it to the receptionist ... Everybody knows your piss”*

In contrast, other participants cited fear of unwanted results as their reason for not undergoing sexual and non-sexual health appointments.

*“... it’s nerves ‘cause I know that my mum had, um, the same thing [cervical screening] and there is cancer sort of round about that sort of area in my family ...”*

*“I’ve never been tested for anything ... I’m scared of the results”*

The perceived emotional costs of sexual health discussion and intervention were compounded by a lack of social support; some participants were dependent on male partners reluctant to accompany them to appointments.

*“My partner don’t like going to things like that anyway, and ‘cos like I don’t like going out ... I had no-one to go with” [to an abdominal scan]*

Conversely, availability of social support appeared instrumental in enabling attendance at sexual health services.

*“My sister ... she actually ... came with me [for a cervical screen]. It’s only ... at the end ... of the road. But ... before that it had been about 7 years”*

For some participants lack of support and fears surrounding attendance and intervention combined to generate desired or realised use of substances to enable that engagement.

*“Because I was all on my own and I was scared [I got drunk] ... They must have thought I was a right shambles...”* [Participant reflecting on use of alcohol to enable hospital attendance for late miscarriage]

*“If I could get a nice, big dose of methadone one Tuesday and give it a couple of hours to kick in I’d be down that clinic just getting it all done”*

### Low perceived value of undergoing interventions

Low perceived value of undergoing interventions was understood to be a product variously of: confusion over which interventions had previously been received; drug use-related amenorrhoea and subsequent perception of infertility; poor understanding of STI risk and of the potentially asymptomatic presentation of STIs; perceived incompatibility between drug use and good sexual health; and minimisation of risk, trauma and of the value of self-care. These factors deterred sexual health care access, and indicate the potential for sexual and reproductive health education and communication to improve service uptake.

*“I can’t remember, if, the doctor actually did, do something. I don’t know ... if it stopped me getting, um what do you call it ... they get vasectomies and we get ...”*

*“the last one [child] I was um, on heroin and methadone, and er I wasn’t having periods, so, um, I wasn’t using contraceptives ...”*

*“I’m never really worried about it [catching STIs or HIV] ... ‘cos I’m quite fussy who I sleep with”*

*“I don’t feel very ill so there can’t be much wrong with me. I’ve been with the same man for four or five years, how can there be anything wrong, I would have noticed by now”*

*“... it was almost forced and ... I was at a low mental thing ... it was just easy to get it over and done with and I wasn’t really bothered about myself then ... So I didn’t really care ...”*

An implicit notion that substance misuse carried specific stigma around female sexual behaviour was expressed firstly through participants being at pains to disassociate themselves from drug users they considered to be sexually promiscuous, and secondly through links drawn between heavy drug use and

greater sexual risk (and perceived immorality). This perceived association between drug use and sexual risk was understood as both a perceived incompatibility between sexual well-being and drug use, and as being instrumental in fear of STI screening and the significance of unfavourable results.

*“I had three partners from the age of 16 to 22 you know ... I’d done nothing wrong so I felt confident about going ... Since the drug use and the spiral down into hell, I felt like there could be something I don’t wanna hear”*

Perceived incompatibility between sexual well-being and drug use was also extant in the notion that ‘getting clean’ from drugs and getting a ‘clean’ bill of sexual health went hand-in-hand; many participants related how they had (or intended to) address various aspects of their sexual health screening once they were ‘in recovery’ from drug use, rather than before.

*“I had a smear test then when I ... gave up smoking crack and I had Hep C testing and the lot”*

Others, however, indicated that although this had been their intention, once in recovery their fears surrounding sexual health interventions precluded attendance. These data resonate with the previously reported use, and desired use, of substances to enable access.

*“I wasn’t going to think about anything except not drinking, ‘cause if you start worrying about what might be wrong with you when you start sobering up it can get very scary”*

### CONCLUSIONS

Drug-use lifestyle practicalities and stigmas, the legacy of traumatic experiences, and poor self-regard and self-care were understood to be mutually sustaining factors that act together to reduce the perceived value of sexual health interventions, to present barriers to actual attendance at services, and to create significant emotional concerns around interventions and the social encounters with professionals that these entail. Findings indicate that in the context of pre-existing fears around sexual health discussion, testing and results management, impoverished social and intimate relationships may further deter access to such services and that non-attendance at sexual health (and other) services may be understood as an act self-protective of emotional well-being, limited resources and drug recovery. A participant’s statement that “It’s not that I don’t care, it’s just that I can’t be bothered” encapsulates the low perceived value of interventions and the perceived high costs and efforts involved in accessing them, but also indicates a gap between concern and action, and thus the potential benefit of interventions aimed at minimising these barriers.

The study findings substantiate and illuminate existing evidence in a number of ways. Barriers to access

identified in this study are likely to contribute to the high rates of STIs<sup>3-5</sup> and unintended pregnancy<sup>3, 6</sup> experienced by SMW. Inconsistent use of contraception and family planning services, and negative perceptions of those services,<sup>3</sup> are understood in this study as consequences of a broad range of factors inhibiting both contraception service access, and the use and non-use of contraception itself. In particular, low perceived risk of pregnancy has been identified in previous research.<sup>19</sup> The study findings also extend previous research concerning the high rates of sexual assault, male dominance and social isolation experienced by SMW<sup>9</sup>; by adding valuable information about the impact on health service access, in particular the importance of social support in enabling attendance. Related to this issue, the role of inebriation in managing distress, known to be a key motivation in women's drug use,<sup>15, 16</sup> is understood in this study as both a strategy to facilitate access to services in the absence of social support, and as a barrier to access due to the subsuming nature of drug-use lifestyles or reluctance to jeopardise drug recovery.

Many of the study findings are, by their nature, prone to recall bias in exploring past as well as current sexual health care needs and experiences. In contrast with quantitative studies of SMW, few participants reported exchange of sex. This may reflect the verbalised desire to forget, and avoid discussion of, traumatic and stigmatised sexual experiences; and/or that most participants were engaged with treatment services with associated improvements in their financial and living circumstances. This latter point and the single geographical location of the study may limit transferability. Nor is it known to what degree the findings are transferable to populations of substance-misusing men. Confusion surrounding interventions and types of service provider limited study data richness and may also reduce perceived need for services. Similarly, reluctance to discuss past experiences of assault, sex work and non-use of contraception in the context of sexual health care access is likely to represent a barrier to that access in addition to limiting the dataset.

Participants' avoidance of certain topics – and minimisation of trauma, of risk behaviours and of the potential impact of not accessing services – present complex challenges for both research and clinical practice in this field when viewed as coping strategies that may have both positive and negative impacts for the women concerned.

Many participants raised experiences of sexual assault and removal of children but declined to discuss the impact of this on sexual health service access and uptake. In this regard, interviewees were acutely conscious of the research interview as a potential disruption to the reported coping mechanisms of 'not thinking or talking about' experiences and behaviours. Conversely, many participants volunteered that

the research interview had provided them with a rare and welcome opportunity to think through their sexual health needs and behaviours, such that training non-sexual health providers to initiate sexual health discussions may be effective in precipitating access. These data point to the need for sensitive patient care that recognises the importance of uncovering and addressing sexual health concerns but also the risks to emotional well-being and engagement this entails. Similarly, this study resurrects interesting questions about overlap between counselling and research interviews,<sup>20</sup> and highlights the importance of ethical research practice in pursuing sensitive topics with SMW.

It is important to note that most of the barriers identified are unlikely to be specific to SMW (excepting those presented by a drug-use lifestyle and drug-use stigma), although it is reasonable to surmise they may occur more frequently among this, and other, disenfranchised populations. Nonetheless this study offers unprecedented insight into barriers to sexual health service access among SMW and identifies low uptake of contraception and the impact of sexual assault on uptake of sexual health interventions as areas where further research is warranted.

The barriers identified in this study pave the way for a variety of interventions that address: anticipated stigma; the likelihood of prior traumatic experiences; lack of financial, emotional and hygiene resources; and poor understandings of risk, procedures and symptoms. These interventions have been specified as part of the overarching study of which these interviews were a part. They are to be published separately as a model developed to improve access and reduce sexual health morbidity among this population. A copy of the model can also be requested from the corresponding author. The findings also offer insights to practitioners on how best to engage with SMW in clinical consultations. Initially expressing an interest in the patient's substance misuse issues may help allay their concerns about being 'looked down upon' or otherwise stigmatised by the practitioner. The meta-barriers identified in the findings – low perceived value of sexual health interventions, emotional concerns, and lack of resources to support attendance – may also provide a useful template for discussion with the patient. Acknowledging that accessing and undergoing interventions can be difficult is likely to be a useful starting point from which to build up a rapport with the patient and hence identify their specific sexual health needs and barriers, with a view to the practitioner and patient mutually agreeing a course of action which feels safe, achievable and useful for that individual.

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