In what ways do women experience stigma or embarrassment in relation to reproductive symptoms or in accessing healthcare, and what are the policy responses?

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**Question**

This briefing summarises the evidence on women’s experiences of stigma or embarrassment in relation to reproductive symptoms or in accessing healthcare, and the policy responses, from 1999 to 2017.

**Key messages**

- The evidence base on women’s reproductive health stigma is broad, encompassing every aspect of female reproduction as well as psychological responses and enactment of human rights.
- Girls and young women find it difficult to view menstruation positively as natural function because of the pervasive gender stereotypes that form the basis of the taboo about menstruation.
- The term ‘repeat abortion’ intensifies women’s experiences of shame and is unhelpful, damaging and can increase stigma.
- Disclosure about infertility or treatment may only help reduce stigma if women discuss their infertility with others in similar circumstances.
- There is a general lack of knowledge and understanding about the range of perinatal mental health conditions amongst healthcare professionals and women themselves, and the stigma of mental illness can prevent women from seeking the help they need.
- Barriers to healthcare access include, lack of confidentiality and privacy, shame, embarrassment, stigma, cultural and religious beliefs, intimate partner violence and/or family control.
- Current policies and guidance do not currently incorporate an understanding of women’s lived experience of stigma and discrimination to inform approaches and interventions. This review highlight some of the diverse ways in which stigma impacts on experience. A holistic policy response is required.
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Background

The evidence base on women’s experiences of reproductive health embarrassment and stigma is broad and multifaceted, encompassing every aspect of female reproduction, as well as psychological responses and enactment of human rights. Stigma is defined as ‘a mark of disgrace associated with a particular circumstance, quality, or person’ and is perceived and experienced at every stage of women’s reproductive life course, including menarche, menstruation, pregnancy (infertility, maternal mental health, abortion) and menopause(1). This briefing provides an overview of the experiences of women in the UK that have been reported in the literature and describes the policy responses to date.

Policy responses

To date, reproductive and sexual health policies and guidance only go as far as to acknowledge the fact that service users experience reproductive health stigma and discrimination and that this needs to be addressed:

- Public Health England says that ‘stigma and discrimination should be combatted through education and an open and honest culture around sexual health’(2).
- Scotland aspires to ‘a society and culture whereby the attitudes of individuals, the public, professionals and the media in Scotland towards sexual health are positive, non-stigmatising and supportive’(3).
- The Royal College of General Practitioners (RCGP) states that ‘Quality SRH (sexual reproductive health) should enable patients to have a choice of contraceptive methods delivered by well-trained professionals without fear of harassment or stigma’(4).
- The Welsh Assembly seeks a ‘shift towards a culture that is more comfortable talking about relationships, sexuality and sexual health(5)’.

Current policies and guidance do not provide adequate insights into women’s lived experiences of stigma and discrimination to inform approaches and interventions. The evidence highlights a need for a holistic policy response based on listening to women’s voices.

Women’s experiences of embarrassment and stigma

Menstruation

In a survey of 1000 UK girls and young women aged 14-21, nearly half (48%) said that they are embarrassed by their periods and more than half (59%) said that they had received negative remarks about their perceived behaviour and mood whilst on
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their period(6). Almost half of the girls surveyed (49%) had missed school because of their menstruation symptoms and of those more than half (59%) had made up a lie or an excuse to cover up the real reason. Common experiences of teasing and ridicule from male peers in school reinforces feelings of shame and embarrassment and the desire for secrecy and concealment(7). The evidence shows that the taboo about menstruation in the school setting is entrenching and institutionalising stigma(6, 7).

Menarche and menstruation are socially and culturally constructed as embarrassing, shameful and something to be hidden(7). Menstrual blood is seen as dirty and menstruation is perceived as an illness that needs to be managed, girls often feel that something internal has gone wrong(8). Girls and young women find it difficult to overcome negative perceptions and to view menstruation positively as natural function because of the pervasive gender stereotypes that form the basis of the taboo about menstruation(7).

A significant number of girls are asked not to talk about their periods in front of their parents(6). The response of parents to girls’ menstruation can shape their perceptions and experiences, which can in turn have an impact on their self-image(6, 9). Whilst there is not a great deal of evidence on the impact of parents’ responses to their daughters’ menarche, there is some evidence to suggest that mothers are unwittingly perpetuating the taboo of menstruation by modelling negative responses based on their own experiences(9).

Women with inherited bleeding disorders (IBD) can suffer from abnormal bleeding for many years before diagnosis. Most are pragmatic about their IBD and are able to manage the symptoms, but a substantial subgroup experience stigmatization, isolation and bullying. The evidence shows that those who are properly diagnosed receive appropriate care and feel well supported but those who are not do not receive adequate care and support find it more difficult to manage and cope with their condition(10).

**Infertility**
According to a national survey assessing the impact of fertility problems, infertility and treatment causes high levels of distress(11). Although the survey did not exclusively assess the impact of infertility on women 98% of the respondents were women and therefore the results largely reflect female experiences. Those most vulnerable to high levels of distress were women who had unsuccessful treatment, those who had difficult relationships and those lacked sufficient social support(11, 12).

A paper assessing the relationship between stigma, disclosure patterns, support and distress in new attendees at an infertility clinic, tested the hypothesis that high perception of stigma is associated with reduced disclosure to others, leading to lower levels of support and higher levels of distress(13). Women reported higher levels of
In what ways do women experience stigma or embarrassment in relation to reproductive symptoms or in accessing healthcare, and what are the policy responses?

Fertility related stigma than men despite higher levels of disclosure. The authors believe that this may be because women are more shame conscious and are therefore more vulnerable to negative social experiences. Women carry a disproportionate level of blame when a couple is infertile and there may be secondary effects of childlessness such as reduced social status(12). The paper concludes that encouraging women to widely disclose their infertility status in order to receive greater social support is not necessarily in their interests, and that disclosure may only help reduce stigma if women discussed their infertility with others in similar circumstances(13).

Many women also reported that fertility problems and treatment had an adverse impact on their careers. Less than a third of respondents of the national survey reported the existence of supportive workplace policy and only 41% said they received really good support from their employer(11).

**Maternal mental health**

Mental health problems are very common in the perinatal period but research undertaken by the Royal College of Obstetricians and Gynaecologists shows that there is a general lack of knowledge and understanding about the range of perinatal mental health conditions amongst healthcare professionals and women themselves(14). Women reported that healthcare professionals frequently focussed on their physical health conditions and neglected their mental well-being. If a woman experienced a physical condition such as hyperemesis gravidarum (severe nausea or vomiting during pregnancy) or pelvic girdle pain, they were often left feeling isolated and anxious whilst their physical symptoms were treated(14, 15).

Women cited embarrassment, the stigma of mental illness, concerns about mental health problems being noted in their medical records, and even fear of having their babies taken away from them, as the main reasons for their reluctance to talk to a healthcare professionals about their mental health problems(14, 16). Women felt judged and stigmatised if they could not breastfeed their baby or chose not to. Many felt blamed when they found breastfeeding difficult and this was hard to cope with when they already felt like a failure(14).

**Abortion**

Even though the National Health Service (NHS) funds almost all abortions in England and Wales, less than a third are provided by the NHS. The vast majority of abortions are provided by the independent sector. The author of a paper on abortion stigma in the NHS argues that ‘the invisibility of abortion in the NHS perpetuates the social norm that abortion is uncommon (and therefore deviant), which in turn contributes to the stigma’(17). They assert that less reliance on the independent sector would allow NHS staff to provide the full range of women’s reproductive health services and NHS provision would facilitate wider recognition of abortion as part of women’s reproductive life(17).
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The recent growing international interest in identifying the reasons for repeat abortions in order to reduce the rate and improve health outcomes for women, has it seems, inadvertently lead to the stigmatization of women who seek more than one abortion. Recent qualitative research shows that the term ‘repeat abortion’ intensifies women’s experiences of shame and is unhelpful, damaging and can increase stigma(18). The research highlights the need to carefully consider the language used to describe women and their reproductive health.

**Menopause**

According to a 2005 survey of European women, comparatively more women in the UK reported that they were affected by the menopause leading to a larger decrease in the quality of life than their European counterparts. The results of the survey showed that the impact of the menopause on women’s lives was less significant in France and Spain. The authors’ believe that the greater part of the observed difference is likely to be due to cultural expectations and perceptions about the menopause(19).

Women describe their experiences of early menopause as an emotional seesaw of shock, denial, anger and loss. Young women experiencing premature menopause find it difficult to come to terms menopause because it represents the loss of reproductive potential and is associated with older women. Menopause can therefore affect young women’s sense of femininity and identity. The negative social constructs make it difficult for women to maintain their self-esteem and control over their lives(20).

Research exploring the experiences of women with mild to moderate intellectual disability found that there is a lack of understanding about what menopause is and its significance on a woman’s reproductive capacity. The research shows that women with intellectual disabilities also have low levels of choice and autonomy when it comes to the management of their symptoms(21).

A paper investigating the views and attitudes of British-Asian women found that whilst many saw menopause as natural phenomenon, almost half were afraid of it(22). The research highlights the need for greater support to help women understand what the menopause means for them physically and emotionally, and how they can manage the symptoms. The recommendations are that service providers should offer clinics run by female health professionals and information should be provided in a language that Asian women can understand.

A study of women’s experiences of working through menopausal transition in the UK found that menopausal symptoms can cause challenges for some women at work(23). Employed women experience the full range of symptoms at work, but those that are particularly problematic in the employment setting include, poor concentration, tiredness, poor memory, feeling low/depressed and lowered confidence. Coping with hot flushes is particularly stressful. Most women are
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unwilling to disclose menopause related problems to their managers. They cite reason such as, it does not affect their work, it is a personal/private issue, and it is embarrassing. Some women perceive a drop in performance whilst others say that their overall performance is not affected because they work harder to compensate for their symptoms(23).

**Other gynaecological symptoms**
The symptoms of polycystic ovarian syndrome (PCO) include, excess hair growth, irregular, absent or disrupted periods and infertility. Society defines feminine women as those with hairless bodies and faces and the capacity to bear children. Women who suffer from PCO describe their experiences as ‘a theft of womanhood’ because their symptoms render them unfeminine and ‘other’. Their sense of freakishness and abnormality can also be exacerbated by the way that their condition is explained to them by medical practitioners, for example in terms of ‘male’ hormones. PCO can therefore be a profoundly stigmatising condition(24).

**Sexually transmitted infections**
One study exploring the reasons why women choose to use specialist sexual health services for sexual health screening found that women’s willingness to access services was mitigated by factors such as embarrassment and perceived stigma. One of the main reasons why women choose specialist sexual health services is because healthcare professionals are sensitive to their emotions and comfort, and their feelings are appropriately managed(25). The evidence shows that women choose specialist sexual health services as an alternative to primary care services because they believe they provide greater anonymity and confidentiality(25, 26).

**Barriers to seeking healthcare**
A range of barriers prevent women from accessing appropriate healthcare for their reproductive health needs including, lack of confidentiality and privacy, cultural and religious beliefs, shame, embarrassment, and stigma. (25-28). The reaction or anticipated response of healthcare professionals to women seeking reproductive health interventions is a commonly cited barrier(27, 29-31).

**Stigmatising conditions**
A study examining the attitudes of young multi-ethnic inner city women to sexually transmitted infection (STI) screening found that, firstly they did not see themselves as candidates for screening, and secondly they were afraid of the stigma associated with testing. They preferred confidential testing and therefore despite attending their general practice for non-sexual health matters they did not consider general practice to be an option for STI testing(26).

In the case of abortion the health professional may exercise their conscientious objection (CO) and opt out of providing advice and care on the grounds that abortion is morally questionable(32, 33). According to one paper the prevalence of CO and its
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Questionable deployment is increasing and threatening women’s access to timely abortion (33). The paper’s author argues that whilst the human right of freedom of conscience and religion entitles healthcare professionals to conscientiously object, these rights have to be balanced with women’s right to dignity and autonomy in reproductive health. Those who have considered CO in relation to reproductive health point out that healthcare professionals owe women a duty of care that needs to be taken consideration when CO is applied (32, 33).

Some women are seeking abortions outside the formal healthcare setting altogether. According to these women the main reasons for doing so include the perception or experience of judgmental attitudes and stigma, concerns about privacy and confidentiality, and for some, the fear of strong disapproval on religious and cultural grounds leading to shaming, shunning and potentially violence against them (27).

Hyperemesis gravidarum can be a distressing and debilitating condition if it is not properly managed. Research looking at women’s experiences of the condition shows that they often encounter scepticism about the severity of symptoms and are made to feel like ‘time-wasters’. Lack of understanding and inadequate support from primary care services is clearly a barrier that can prevent women from accessing the care they need (15).

**Stigmatised groups**

Women in the UK face many common barriers across the spectrum of reproductive health but some groups of women face specific barriers. For substance misusing women one of the main barriers to accessing sexual health interventions is the emotional cost of interactions with healthcare services and healthcare professionals (34). Low self-esteem resulting from the belief in the incompatibility between drug-use and sexual and reproductive wellbeing means that drug misusing women lack the emotional resources to discuss sexual histories and to cope with tests and unfavourable results (28, 34). Attending to their sexual and reproductive health is sometimes seen as part of the recovery process rather than as a separate need that can be met independently of drug treatment (34).

According to a paper on lesbian and bisexual women’s human rights and sexual rights lesbian and bi-sexual women have to ‘negotiate’ their sexual health (29). The barriers they encounter include, fear, previous experience or awareness of others’ experiences of, healthcare professionals’ homophobic attitudes and responses. They face three choices when accessing sexual health services and advice, first they can choose not to disclose their sexuality meaning they may not receive appropriate advice, second they delay accessing services for fear of discrimination and third, they access healthcare and disclose their sexuality but risk experiencing stigma and discrimination. The paper’s author asserts that lesbian and bisexual women experience sexual health inequalities resulting from a ‘heterosexist’ (the presumption of heterosexuality) approach to reproductive health provision (29).
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**In conclusion**

It is evident from the research that many women are perceiving and encountering stigma and discrimination in relation to their reproductive symptoms and circumstances, and this is a significant barrier that prevents them from obtaining the care and support that they need. The literature describes the wide range of lived experiences of different groups of women. It highlights the need for service improvements and greater awareness and education amongst healthcare professionals, families and society as a whole; but there is also recognition that system and cultural change is not easily achieved(7). What is clear is that women need greater empathy and support to help them manage their reproductive health symptoms and to deal with the stigma and discrimination that they encounter(10, 13, 14, 23, 28, 31, 35, 36).
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Endnote database matrix showing the highly relevant papers with key

This database can be obtained on request.

KLS Evidence Briefing

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References

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