

Does the historical stigma of hyperemesis gravidarum impact health care professionals' attitudes towards and treatment of women with the condition today? A review of recent literature

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ORIGINAL

Hyperemesis gravidarum (HG) is a condition affecting pregnant women in which extreme levels of intractable nausea and vomiting lead to dehydration, malnutrition and a host of other complications (Dean & Gadsby 2013). Affecting 1–1.5% of the pregnant population (Einarson *et al* 2013), the condition sees around 10,500 women per year requiring in excess of 25,000 hospital admissions (Gadsby & Barnie-Adshead 2011b). However, this figure does not take into account the estimated 30% of women who suffer high levels of morbidity from nausea and vomiting in pregnancy (NVP) without accessing secondary care services (Gadsby & Barnie-Adshead 2011a).

Although the exact aetiology of HG remains elusive, the biological nature of the condition has been well-established for many years (Munch 2002a), which ought to have put to rest the early 20th century psychodynamic theories of hysterical women mentally rejecting their fetus. Yet as recently as 2004, women in Paris were being subjected to 'Near total isolation' in a room with no light, and subjected to psychological interrogation so they would reveal their desire for abortion (Karpel & de Gmeline 2004). As shocking as that sounds, it was established practice from the mid-1930s when such psychodynamic theories gained popularity and Atlee (1934) published instructions on treating HG as follows:

'My routine is as follows: From the moment the patient enters hospital she is denied the solace of the vomit bowl. She is told that, in the event of not being able to control herself, she is to vomit into the bed; and the nurse is instructed to be in no hurry about changing her. . . I assure them very dogmatically that they are going to stop vomiting at once, and that they will leave the hospital perfectly well in a week.'

Recent years have seen substantial improvements in the care and treatment of women with HG, such as the establishment of specific HG day treatment units (Ajufo 2013, Hordern *et al* 2013, Coleman *et al* 2014, Dean 2014b), where a woman can receive rapid intravenous (IV) rehydration and medication during the day and return home to her family overnight. However, there are still reports emerging from women across the UK that the condition is considered to be psychological by many health care professionals (HCPs) and that the stigma associated

with the condition is a barrier to accessing evidenced-based treatment (Pregnancy Sickness Support, British Pregnancy Advisory Service 2015).

To explore the extent of this phenomenon, with a view to influencing current practice, we will seek to research the question: Does the historical stigma of hyperemesis gravidarum impact health care professionals' attitudes towards and treatment of women with the condition today?

Method

The following databases were accessed for the search: CINAHL; AMED; MEDLINE; SocINDEX; PsychArticles; Joanna Briggs Institute; Embase. When combining all aspects of S+PI+D+E+R (as per Table 1) with the Boolean operator 'AND' no results were generated on any of the databases. Therefore the searches were redone with the following combination of Boolean operators: [S AND PI] AND [D OR E OR R].

This generated 77 results from the two searches which comprised the above databases.

Study selection

Figure 1 (below) displays the study selection process.

Review of the literature

Table 2 contains a summary of the articles reviewed (below).

It is striking that there is a significant lack of rigorous recent research addressing this issue given that numerous studies, excluded from this review, were conducted in the 1990s and found that the stigma

associated with HG had a negative effect on the opinions held by HCPs, which in turn had a profound impact on the experiences of women with HG (Mazzotta *et al* 2000, Munch 2000, Munch 2002a, Munch 2002b, O'Brien *et al* 2002, Soltani & Taylor 2003, Munch & Schmitz 2006, Munch & Schmitz 2007, Locock *et al* 2008).

There can be little doubt from the six reviewed papers that a stigma remains tenaciously attached to HG across English speaking countries. All the studies found that women continued to have their symptoms dismissed and trivialised well into the 21st century. Poursharif *et al* (2007), Poursharif *et al* (2008) Sykes *et al* (2013) and Dean (2014b) all found that women reported high levels of satisfaction and praise for their HCP when they explicitly 'believed' in the physical and severe nature of the condition. All the papers are from UK populations, with the exception of the two Poursharif *et al* (2007, 2008) papers which were conducted in the USA but gleaned 182 responses from English speaking women across the globe, particularly the UK, Australia, New Zealand and Canada.

The two Poursharif *et al* (2007, 2008) papers are from the same data set, obtained through a self-selected online survey of women recruited via a specific HG website. However, although there is

Table 1. Search terms for the research question

Spider tool	Search terms
S – Sample	Hyperemesis gravidarum OR pregnancy sickness OR nausea vomiting pregnancy
PI – Phenomenon of interest	Stigma OR historical context OR attitudes
D – Design	Questionnaire OR survey OR observation OR focus group
E – Evaluation	Patient experience OR attitudes OR views
R – Research type	Qualitative OR mixed methods

some overlap with the demographics, the two papers analyse different questions from the survey, which was conducted over two years as part of a condition registry project. The questions utilised in Poursharif *et al* (2008) are similar to those used in other studies, including those validated for use with HG patients by Munch & Schmitz (2007) in their Hyperemesis Beliefs Scale, and therefore have more validity. Whilst the questions analysed in Poursharif *et al* (2007) could have introduced bias to the responses women gave, their analysis produced statistically significant results and they were careful to control for reported severity.

Figure 1: Exclusion and inclusion criteria for article selection

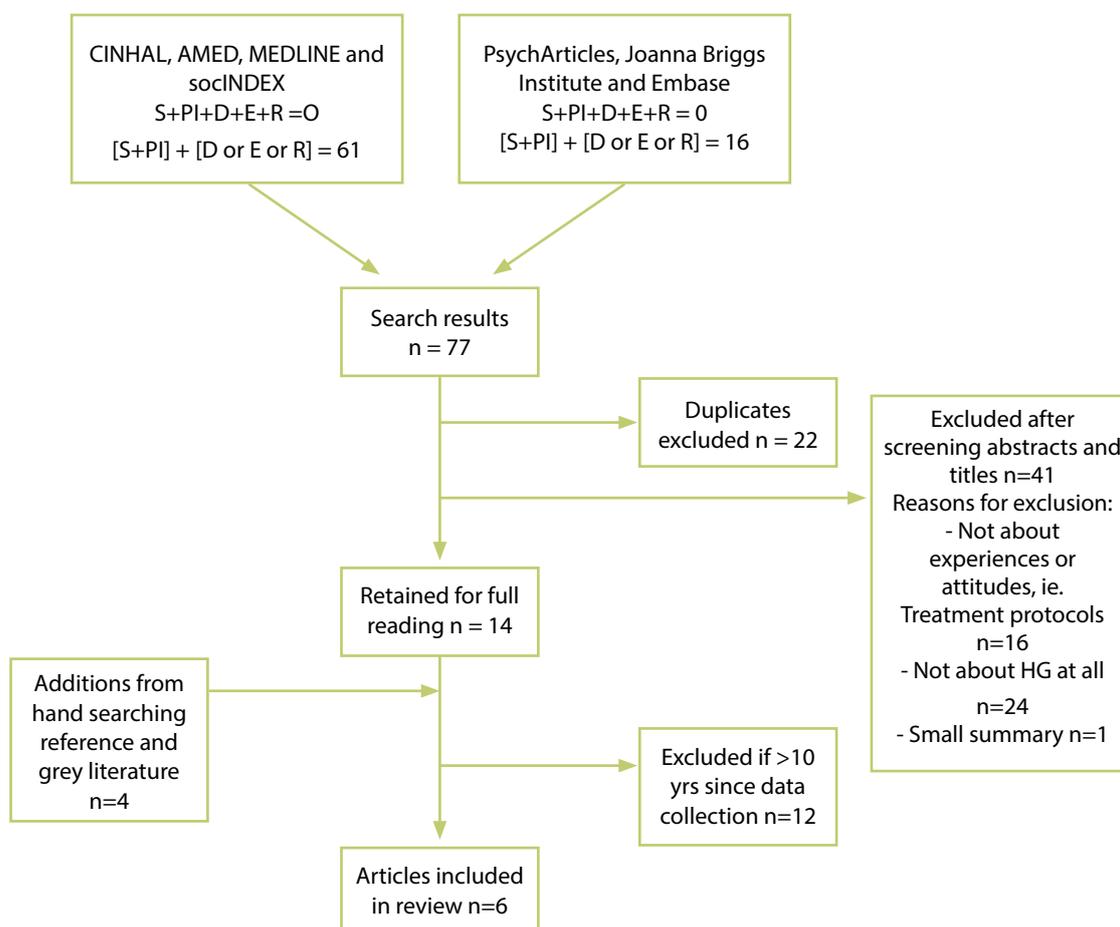


Table 2. Summary of literature included in review

Title	Reference	Methods	Findings
Understanding the stigma of hyperemesis gravidarum: qualitative findings from an action research study	Power <i>et al</i> (2010)	Qualitative – in-depth interviews with 18 women from a purposive sample and also focus groups of 60 staff.	HG patients considered ‘unpopular’ among staff. Women are aware of the stigma associated and this negatively impacts on well-being.
The psychosocial burden of hyperemesis gravidarum	Poursharif <i>et al</i> (2008)	Cross-sectional qualitative online survey of open-ended questions. 808 participants. Self-selected and not population based.	The psycho-social burden of HG is profound yet underappreciated by HCPs. Validation of the condition goes some way to alleviating the burden.
I could not survive another day. Improving treatment and tackling stigma: lessons from women’s experiences of abortion for severe pregnancy sickness	Pregnancy Sickness Support, British Pregnancy Advisory Service (2015)	Cross-sectional online survey of 71 anonymous women who had undergone termination for HG in the last 10 years. Self-selected via internet so no population base.	Women chose to terminate an otherwise wanted fetus due to the severity of symptoms. Many of these women are refused safe treatments and there appears to be a strong stigma attached to taking medication in pregnancy which is negatively affecting their care.
A patient experience of hyperemesis gravidarum and how the midwife can support her care	Dean (2014b)	Self-reported case study by a registered nurse who suffered the condition – included as it is a peer reviewed paper in a reputable journal and claims to support other literature discussed in this review.	Article gives EBP recommendations and illustrated this with a personal story of experiencing both poor care and excellent care.
Elective pregnancy termination in a large cohort of women with hyperemesis gravidarum	Poursharif <i>et al</i> (2007)	Cross-sectional qualitative online survey of open-ended questions. 808 participants. Self-selected and not population based. Their answers are compared to women who had not terminated.	Women who had terminated for HG were three times as likely to report that their HCP was uncaring or lacked understanding. Other reasons included fear of safety of treatments for HG.
Seeking medical help for nausea and vomiting in pregnancy and hyperemesis gravidarum in primary care	Sykes <i>et al</i> (2013)	Nineteen women recruited through an advert on PSS website. Self-selected population. In-depth qualitative interviews conducted with open-ended questions. Thematic analysis with sentence by sentence coding to identify themes which were then checked by other authors until agreement was met.	Poor communication with HCPs was a major theme with many finding they were dismissive or uncaring. The psychological burden for women taking medication in pregnancy was added to by HCPs. Where women were ‘believed’ satisfaction was high.

When comparing women who had terminated, with a control group who had not, 52% of those who had terminated reported that the HCPs they encountered were either uncaring or did not realise how sick they were, compared with 24.5% of the control group (odds ratio 3.34, 95% confidence interval 2.21–5.05, $P < 0.001$).

Pregnancy Sickness Support & British Pregnancy Advisory Service (2015) have taken a more qualitative approach to investigating the reasons for women deciding to terminate an HG affected pregnancy, which may be a more appropriate method for

exploring this sensitive issue. Their paper simply employs descriptive statistics and direct quotes from open-ended questions to illustrate the findings. While this is also a self-selected population of 71 women recruited through internet social media sites for women with HG, and is likely to be biased towards negative experiences as a result, the methods employed appear to have generated more meaningful results for the UK health care system in relation to the research question they were aiming to answer, compared to Poursharif *et al* (2007) on an almost identical topic. Hunter (2012) suggests that online surveys help with the discussion of sensitive subjects

due to the anonymity created online. In terms of this review, the results are very recent, from data collected this year, and clearly demonstrate that the stigma historically associated with the condition continues to impact on the attitudes of HCPs and their treatment of women with HG. The report highlights not only that the pernicious psychosocial theories associated with HG are ongoing, but that there is also an issue surrounding the perceived safety of medication use in pregnancy for the condition. Pregnancy Sickness Support & British Pregnancy Advisory Service (2015) propose that the thalidomide tragedy of the 1960s, in which a highly teratogenic drug was used for numerous pregnancy-related ailments and particularly NVP, continues to cause tragedy for pregnant women who are refused medications for HG, despite evidence they are safe and effective, because of perceived risks to the fetus. Their qualitative descriptive data clearly demonstrates this as an ongoing problem of a previously identified phenomenon (Mazzotta *et al* 1999, Koren & Levichek 2002).

The impact of HCP concern over medication in pregnancy is also evident in Sykes *et al* (2013). This qualitative research involved in-depth interviews with 19 women who have suffered HG or severe NVP. Thematic analysis using sentence by sentence coding identified major and sub-themes which were validated by agreement with the other paper's authors. While the methods employed appear rigorous, the sample was recruited through a website about the condition, as was the case in all but two of the papers reviewed. This is likely to be a reflection of the target population being women of reproductive age and therefore below 45 years old and engaging with life 'online', however it inevitably introduces bias and makes the results difficult to generalise from. Like Pregnancy Sickness Support & British Pregnancy Advisory Service (2015) and Poursharif *et al* (2007, 2008), the results from these interviews clearly demonstrate that there is an ongoing stigma associated with the condition in relation to its perceived psychogenic origin. Communication is a key theme and women report the need to 'educate their healthcare professional' and validate their symptoms (for example by taking along their partner to corroborate their experience) before being able to access treatment. Sykes *et al* (2013) also found that when women encountered supportive HCPs, who they felt believed their experience, they placed great value on being given clear advice and information to make informed choices.

Of the research reviewed, the Power *et al* (2010) paper is perhaps the most striking, not only for its results, highlighting the profound stigma still impacting women's care, but also for its methodological rigour. A purposive sample of 18 pregnant women was recruited for in-depth semi-structured interviews. Through access to an interpreter, women who did not speak English were

able to take part, which is in marked contrast to the various online surveys which have thus far explored the research question. This is the only recent study of its kind which recruited women through an NHS gynaecology unit. During the same data collection period, the researchers conducted multiple focus groups with medical and nursing staff from the same unit. Unfortunately, despite rigorous analysis of the data, which was collected until saturation occurred, the emerging themes were only validated by the findings from the same author's quantitative research which was occurring at the same time, and it is not explicit if the other authors, or indeed the participants, assisted in validating these themes. Although this may not be a problem *per se*, and indeed Power *et al* (2010) provide rationale for their strategy, as recommended by Glaser (1965), their own bias is not addressed and it is hard not to get the impression that the authors have had personal experience of the condition which may have influenced their findings and discussion.

That said, the findings in Power *et al* (2010) are extremely relevant to the research question that this paper addresses. Even allowing for the potential of research bias, the quotes from the staff focus groups clearly demonstrate the ongoing stigma associated with HG and the issues faced by women with the condition. The paper highlights two relevant associated themes for disbelieving women: that the condition is psychological and/or social in origin; the women are not actually ill but are exaggerating so they can come to hospital and have 'time off'. Furthermore, women with HG are found to be 'unpopular' patients, and staff complained that they were uncommunicative and unrewarding to care for. Through the in-depth interviews with the patients in this study it was apparent that they were aware of their unpopular status among HCPs, and this had a further negative psychological impact on them. In addition to the above criticism regarding author bias, a further criticism of the otherwise solid Power *et al* (2010) research is that it encompasses only one hospital in the UK and the results are therefore not generalisable beyond that setting. That said, the other research included in this review would indicate that the problems highlighted by Power *et al* (2010) are indeed widespread and ongoing.

Dean (2014b) adds to the generalisability of the other articles despite being a self-reported case study. The author, a nurse herself, describes encountering both the dismissive attitudes described so far and 'scaremongering' by doctors who were nervous to prescribe medication in pregnancy. However, it is interesting to note that Dean (2014b) sought out a new physician prior to her third pregnancy and, like Poursharif *et al* (2008) and Sykes *et al* (2013) where HCPs provide validation of the condition, she reports excellent treatment and high satisfaction.

Discussion

From the evidence presented in the reviewed papers, it is clear the stigma attached to HG is ongoing and severely impacts the care and treatment provided by HCPs. However, there are serious methodological flaws with a number of the papers whose authors and datasets overlap. This highlights the sad paucity of interest in the condition, which from this literature and more, clearly has a profoundly negative impact on the physical and mental health of the women who experience it. That research into a significantly expensive and problematic condition is lacking is in itself an indicator of the stigma associated with it. Yet the psychosocial stigma found to be prevalent in these papers has not always been present. Munch (2002a) provides an interesting history of the condition, citing numerous texts as far back as 2000 BC, in which vomiting in pregnancy is described as a biological condition which warrants serious consideration to prevent maternal death. She proposes that the controversy over biological-psychological aetiology was a product of two compounding factors. Firstly, advances in medical treatment: the discovery of IV fluid replacement early last century saw a dramatic reduction in the deaths associated with HG. Secondly, this was compounded by the fashion for psychoanalytic theories, which particularly infiltrated matters relating to women, femininity, sexuality and childbearing (Munch 2002a).

These misconceptions about the condition's aetiology, in the context of social history, are almost understandable up until the later part of the last century as further authors, such as Fairweather (1968), fuelled the theory of an hysterical origin and a symbolic rejection of the fetus. However, with the rise and growth of evidenced-based practice though the 1970s and 80s (Law & MacDermid 2014) it seems shocking that as recently as 2010, Power *et al* found these attitudes prevalent and negatively impacting on care in a large UK teaching hospital. Although the remaining research papers in this review are predominately self-selected samples recruited through websites, the number of women who have taken part in them would certainly lend credence to the notion that Power *et al*'s (2010) findings are not limited to the hospital, nor the year, in which the research took place.

During the review of the papers it became clear that the stigma associated with the condition is two-fold. As discussed above, the psychological aetiology stigma still persists and impacts on the care and treatment provided by HCPs. However, a second historical stigma became apparent from the papers reviewed: that of medication use in pregnancy.

There are multiple treatments available in the UK for safely and effectively treating most cases of HG (occasional extreme cases are unresponsive even to combinations of the strongest medication) (Dean

2014a). Yet despite decades of use without evidence of teratogenic effects, the concerns over the safety of medications in pregnancy following the Thalidomide tragedy is still an overriding theme, not just among HCPs as described in Pregnancy Sickness Support & British Pregnancy Advisory Service (2015) but also among the patients themselves. Poursharif *et al* (2007) found that fear over potential teratogenic effects was a reason that contributed to 22% of respondents deciding to end their pregnancy.

These findings raise serious ethical questions as to the informed consent procedure for women undergoing termination for this condition, as Pregnancy Sickness Support & British Pregnancy Advisory Service (2015) point out that many women are given incorrect or misleading information about the treatment options available. Furthermore, Pregnancy Sickness Support & British Pregnancy Advisory Service (2015) hypothesise that the stigma of taking medications for this particular condition is stronger than with other non-pregnancy-related conditions occurring in pregnancy. For example, they say that steroids are used in early pregnancy for a range of pre-existing conditions such as Crohn's disease, ulcerative colitis and arthritis, yet they are commonly refused for treatment of HG which has failed to respond to anti-emetics. This is supported by Taylor (1996) and Al-Ozairi *et al* (2009) who present safety and efficiency data in support of the notion that steroids should always be offered prior to termination for HG. Despite the shortcomings in the recruitment and methodology of the Pregnancy Sickness Support & British Pregnancy Advisory Service (2015) paper, it is clear that evidenced-based practice has not always been applied to these women's treatments, some 20 years after Taylor's (1996) published research.

Despite decades of research into the stigma associated with HG, and the profoundly negative impact this has had on women and pregnancy outcomes from 1968 to the early 2000s (Soltani & Taylor 2003), it is clear from this literature review that little has moved on. Although this review was limited to papers published in the last ten years, the 1990s saw numerous studies into the negative attitudes held by HCPs regarding HG and the impact this had on care (Mazzotta *et al* 2000, O'Brien *et al* 2002, Munch 2002b, Munch & Schmitz 2006, Munch & Schmitz 2007). And yet it would seem that the negative stigma and subsequent impact on care remain the same today as ten years ago. Therefore the question remains: how we can change the negative attitudes towards women with HG so that they may receive evidenced-based care for this debilitating condition in the 21st century?

Actions for clinical practice

It is clear from the above review that there remains a significant negative and influential stigma surrounding both the cause and treatment of hyperemesis.

Therefore the question of how practice can be improved in light of this review must be addressed. The following action points will focus on how the above evidence can inform reader's clinical practice.

Understanding the physiological aetiology to reduce the psychodynamic stigma

Power *et al* (2010) and Dean (2014b) both discuss the frustration staff can feel about the condition due to the lack of known 'cause and cure', and highlight that feelings of powerlessness in the staff are likely to compound the feeling of stigmatisation for the women in their care. Furthermore, it is established throughout all the literature reviewed that the notion of a psychological aetiology has a particularly negative impact on patients. Therefore a further focus of education should be the physiology of the condition. The problem with this approach is that the underlying cause of HG is, as yet, elusive and the condition is likely to be multifactorial, however various symptoms can be explained physiologically. For example, Power *et al* (2010) built on earlier research in which HCPs describe women with HG as uncommunicative and frustrating to treat, a view supported by Dean (2014b). Education for HCPs could include the evidenced-based reasons for this perceived lack of interest in communication, ie that the physical activity of talking can induce vomiting (Sykes *et al* 2013); HG can induce depressive symptoms in women which may also reduce a desire to talk (Swallow 2010); hypocalcaemia induced by vomiting can lead to lethargy and depressive type symptoms making communication difficult (Shehmar 2015). By ensuring education on this topic is accessible to clinicians, this mismatch between stigma and reality can finally be overcome (Law & MacDermid 2014). Furthermore, the impact of such education could be directly evaluated for whether it effectively reduces previously held opinions.

Holistic assessment of quality of life to improve understanding of a woman's experience of HG

Within our research, despite an instance on validating the physiological nature of HG, all the studies reviewed suggest that clinicians need to be educated to the extent and diversity of the psychosocial impact HG can have on a woman, and indeed her family. Poursharif *et al* (2007) conclude that educating professionals about the psychosocial burden of symptoms could actually mitigate the extent to which they are experienced by women. Power *et al* (2010) suggests that 'a systematic and holistic assessment' of women when they first present is required and Sykes *et al* (2013) go further to suggest that HCPs use the Nausea and Vomiting in Pregnancy Quality of Life (NVPQOL) questionnaire. This is a validated tool developed by Lacasse & Berard (2008) that HCPs can use to determine the extent to which a woman's condition

is impacting on her life. Poursharif *et al* (2008) conclude that early identification of women most at risk of negative psychosocial consequences would allow care providers to implement comprehensive management plans for them. Implementing the use of the NVPQOL tool would be an achievable action for many readers and it seems reasonable to hypothesise that regular use of this tool would reduce some of the negative views held by staff, as insight is gained into the impact of the condition on the patient. However, the NVPQOL is a time consuming tool consisting of 30 questions, and therefore implementation in a busy clinical environment may not always be practical. Furthermore there is no evidence to suggest that staff learning about, or using, such tools will fundamentally improve the negative stigma they hold towards the condition although such an effect would seem likely.

Improving knowledge of medication in pregnancy through education and research

Pregnancy Sickness Support (PSS) have been working with the Royal College of Obstetricians & Gynaecologists (RCOG) on Green-top guidelines for the treatment of NVP and HG which are clearly needed and thankfully due to be released next year. This will go some way to reducing the concerns of HCPs involved in prescribing and administering medications to women in early pregnancy. Sykes *et al* (2013), Dean (2014b) and Pregnancy Sickness Support & British Pregnancy Advisory Service (2015) all emphasise the need for HCPs to have a better understanding of the evidence for the available treatments, as well as making the information available in an understandable format for patients so that informed decisions can be made in partnership between the HCP and patient.

However, there remains a paucity of evidence for many of the medications currently prescribed, despite decades of use. This is partly due to a lack of international consensus on outcome measurements and diagnosis criteria, making meta-analysis of data almost impossible (Painter *et al* 2015). Therefore it is crucial that ongoing research into HG and its treatment utilises validated tools for the assessment, not just of symptoms, but of quality of life.

Conclusion

Many of the published research studies currently available lack quality and homogeneity. The tight pool of authors means that the evidence is often dismissed as not relevant to individual practitioners and clinical teams, who are likely to be unaware of prejudices they hold. Indeed, accusing HCPs of stigmatising the condition may in itself be a barrier to the demise of unhelpful attitudes.

While online surveys appear to be a convenient way of accessing this population of young, internet-savvy

women, the knowledge base would be improved with more studies like that of Power *et al* (2010) across multiple settings. Furthermore, we need research which has not been initiated by researchers with a clear, but undisclosed bias towards the subject, or, such researchers conducting qualitative research need to be explicit in reflecting on their role within the process. By integrating evidence about how historical stigmas affect care provision into HCP education, we can begin to erode the negative impact such stigmas have and improve the care and treatment for these women.

Conflict of interest statement

Caitlin Dean is the Chairperson for the charity Pregnancy Sickness Support Trust (Charity Number: 1094788, Email: caitlin@pregnancysicknesssupport.org.uk) which provides information and support for women suffering from pregnancy nausea and vomiting. She suffered from the condition Hyperemesis Gravidarum and writes a blog www.pewingmummy.co.uk

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