

## ORIGINAL ARTICLE

# The psychosocial burden of hyperemesis gravidarum

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**Objective:** To describe the psychosocial burden of hyperemesis gravidarum (HG) in a large cohort of affected women, focusing on previously unreported problems.

**Study Design:** Women with HG described their pregnancy history in an open-ended survey administered internationally through an HG website during 2003 to 2005.

**Result:** Of the 808 participants, 626 (77.5%) were American. A large majority (82.8%) reported that HG caused negative psychosocial changes, consisting of (1) socioeconomic changes, for example, job loss or difficulties, (2) attitude changes including fear regarding future pregnancies and (3) psychiatric sequelae, for example, feelings of depression and anxiety, which for some continued postpartum. Women who reported that their health-care provider was uncaring or unaware of the severity of their symptoms were nearly twice as likely to report these psychiatric sequelae (odds ratio 1.86, 95% confidence interval 1.06 to 3.29,  $P = 0.032$ ).

**Conclusion:** Over 80% of a large cohort of women with HG reported that HG caused a negative psychosocial impact.

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## Introduction

Hyperemesis gravidarum (HG) occurs in 1 to 2% of pregnancies,<sup>1,2</sup> and is the most clinically severe manifestation of nausea and vomiting of pregnancy (NVP). It causes weight loss during pregnancy,<sup>3–6</sup> dehydration, electrolyte disturbance<sup>7</sup> and nutritional deficiency, which in many cases can necessitate the use of intravenous hydration therapy or parenteral nutrition.<sup>3,8</sup> HG is the

most common cause of hospitalization in the first half of pregnancy and the second most common cause of hospitalization during pregnancy overall.<sup>9,10</sup> The total direct cost of the 59 000 hospitalizations for women with HG in the United States annually can be estimated at more than \$500M.<sup>8,11</sup> This estimate includes only reported hospital charges, and does not include indirect costs to the mother, including time lost from work or payment for childcare while she is ill.

Nausea and vomiting of pregnancy affects more than two-thirds of pregnancies,<sup>12,13</sup> often interfering with daily activity, impairing social and occupational functioning, disrupting family life and causing time lost from work.<sup>3,4</sup> Gadsby *et al.*<sup>12</sup> reported that 35% of 200 women employed outside their home lost time from work because of their symptoms. Of 243 employed women in Vellacott's consecutive series of 500 NVP subjects, 47% felt that job efficiency was impaired and 25% took time off from work.<sup>13</sup> O'Brien *et al.*<sup>14</sup> found that 120 of 147 women (83%) stated that NVP affected their ability to perform usual daily activities. Because these statistics reflect the morbidity of NVP, they are likely to be gross underestimates of the effect that HG has on a pregnant woman's daily life.<sup>15</sup>

When estimating the severity of NVP, it is common for caregivers to emphasize clinical symptoms, although it has been demonstrated that women's own perception of NVP severity is also affected by its psychosocial consequences.<sup>16</sup> Moreover, psychosocial morbidity is evident even in clinically minor forms of NVP.<sup>17</sup>

The psychosocial burden of HG has been described in several small case series but not in large studies, resulting in only nominal awareness of the functional disabilities caused by HG. Our goal was to describe the psychosocial burden of HG in a large cohort, focusing on problems not previously reported in detail.

## Methods

Women reported life changes secondary to HG in a web-based survey offered through the Hyperemesis Education and Research Foundation during calendar years 2003 to 2005. Women interested in HG found this survey on the internet. This was a cross-sectional, qualitative survey, consisting of several open-ended questions

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regarding women's HG pregnancies (Appendix A); it was not intended to be comprehensive. HG was defined as significant weight loss and debility secondary to NVP, typically requiring medications and/or intravenous fluids for treatment. Qualitative responses were categorized by the investigators. Psychosocial effects of HG were grouped as socioeconomic changes, attitude changes regarding future childbearing and psychiatric effects. Women who reported that they were hospitalized, given home infusion therapy or treated with intravenous hydration, parenteral nutrition or a nasogastric tube were grouped as having relatively more 'severe' HG. Because the survey did not address all treatments, hospitalizations and symptoms specifically, it was probable that these characteristics were under-reported. A woman's report that her health-care provider was uncaring, or did not understand how sick she was, was classified as a 'poor response' on the part of her provider.

All analyses were performed at the level of the woman. Because multiple pregnancies could be reported for each woman, a measured characteristic was considered positive if it occurred during any reported pregnancy. Multivariate logistic regression modeling was performed to examine the report of a poor response from the provider with the psychosocial outcomes, controlling for the reported severity of the HG. All data were analyzed using SAS (v. 9.1, Cary, NC, USA). The study was approved by the institutional review board of the University of Southern California Health Sciences Campus.

## Results

Overall, 808 women from 23 countries participated in the survey, with 77.5% from the United States (Table 1). The mean age was  $30.9 \pm 5.0$  years (median 31.0, range 19.0 to 54.0 years). Nearly all women had attended college (92.8%). Women reported having HG up to 13 times, with a median of 2 times. Gravity was reported up to 15 times with a median of 2, and parity ranged from 0 to 8 times with a median of 1. At the time of the survey, 231 women (28.6%) reported being pregnant, 441 (54.6%) were not pregnant and 136 (16.8%) had an unknown pregnancy status. Of the 545 women with at least two pregnancies, 453 (83.1%) reported at least one recurrence.

Although some women noted improvement in their symptoms as early as 14 weeks of gestation, many experienced symptoms well into the third trimester, and up to 3 days postpartum. One woman stated 'I was sick beginning about 15 weeks, and went straight through to my son's birth. I was hospitalized 3 more times after his birth due to being unable to eat.' At least 22 women (2.7%) specifically noted that symptoms continued until delivery. One noted 'The doctors seemed in disbelief that this could last the whole 9 months.' Severe weight loss was commonly reported. A typical comment was 'I lost 30 and 45 pounds with my first 2 pregnancies in 12 weeks time.' Some severe physical consequences of HG were noted, including arrhythmias secondary

to potassium deficiency, an esophageal tear, pancreatitis, and renal and hepatic failure.

Women reported being exhausted, unable to care for themselves and afraid to leave home. Several women remarked that they almost died, and others stated that they 'prayed' for death or considered suicide. Some comments were

- If I had terminated (and I thought about that and suicide frequently), it would have been because of not working, being unable to shower or dress alone, feeling miserable, with no hope, depression, and not supported by family or friends.
- I was depressed and bedridden for 20 weeks. I wanted to die.

A variety of symptoms were reported by these women during the postpartum period, including very slow recovery of physical strength (reported up to 4 years postpartum), continued food aversion, fear of nausea, hypersalivation (reported up to 6 weeks postpartum) and continuing depression, anxiety, sadness and emotional distress. One woman stated 'Everyone suddenly treats you as totally normal once the baby is born and all forget you were so sick, and yet you don't [forget].'

Treatment appeared to vary by country of residence, with the United States outranking other countries in the reported use of parenteral nutrition, home infusion and ondansetron (Zofran) (Table 1). Women typically commented that doctors were often very conservative regarding giving medication or intravenous hydration.

A large majority of the participants (669 (82.8%)) reported negative changes in the psychosocial aspects of their lives as a result of having HG (Table 2). Although these negative sequelae were described by each woman in detail, some of the problems experienced could be categorized into the following general areas: socioeconomic changes, attitude changes toward future childbearing and psychological sequelae.

With respect to socioeconomic changes, 65 women (8.0%) reported career or educational problems due to HG. Difficulties at work and the need to take sick leave were frequently reported by these women. Some reported losing their jobs because they were hospitalized. Thirty-six women (4.5%) reported that this resulted in financial difficulties. Others had problems with insurance coverage, stating that they were told that ondansetron (Zofran) was not covered unless they had cancer; several reported having difficulty getting their hospitalizations covered. Some comments were

- I am battling my insurance company who refuses to pay for my last ER and hospital bill because they believe I received treatment only to terminate my pregnancy.
- My insurance would not authorize the care my health provider was willing to give me. That was the problem.
- I am financially ruined. I have to start over. I am a single parent and have to live with my parents again.
- Had to sell house as I couldn't work during the pregnancy, so couldn't meet mortgage payments. Now live in smaller house in

**Table 1** Treatment characteristics by country of residence (number, percent, 95% confidence interval)

Characteristic	Australia (N = 43)	Canada (N = 28)	Great Britain (N = 73)	Other (N = 38)	USA (N = 626)	Total (N = 808)	P-value
Intravenous hydration	22 (51.2%)	13 (46.4%)	40 (54.8%)	21 (55.3%)	368 (58.8%)	464 (57.4%)	0.5870
Parenteral nutrition	0	3 (10.7%)	5 (6.8%)	1 (2.6%)	92 (14.7%)	101 (12.5%)	0.0059
Nasogastric tube	0	1 (3.6%)	2 (2.7%)	2 (5.3%)	12 (1.9%)	17 (2.1%)	0.5077
Hospitalization	6 (13.9%)	4 (14.3%)	17 (23.3%)	6 (15.8%)	50 (8.0%)	83 (10.3%)	0.0007
Home infusion	0	1 (3.6%)	1 (1.4%)	1 (2.6%)	44 (7.0%)	47 (5.8%)	0.0942
At least one of the above	24 (55.8%)	17 (60.7%)	48 (65.7%)	21 (55.3%)	400 (63.9%)	510 (63.1%)	0.6548
Ondansetron (Zofran)	18 (41.9%)	3 (10.7%)	14 (19.2%)	1 (2.6%)	377 (60.2%)	413 (51.1%)	<0.0001
No medications	2 (4.6%)	3 (10.7%)	7 (9.6%)	4 (10.5%)	34 (5.4%)	50 (6.2%)	0.3465

**Table 2** Psychosocial outcomes as mentioned spontaneously by survey participants in answer to the question: ‘How has your life or future plans changed after experiencing hyperemesis?’

Outcome	Total (N = 808)
Socioeconomic	136 (16.8%)
Financial problems	36 (4.5%)
Job or school problems	65 (8.0%)
Insurance issues	10 (1.2%)
Marital problems	36 (4.5%)
Family relationship problems	23 (2.8%)
Social isolation	8 (0.99%)
Attitudes regarding future childbearing	614 (76.0%)
Fear of pregnancy	157 (19.4%)
Considering changing or changed mind regarding number of children planned	281 (34.8%)
Considering or planning no more pregnancies	299 (37.0%)
Considering or performed sterilization	47 (5.8%)
Considering or followed through with adoption or surrogacy	24 (3.0%)
Voluntarily terminated at least one pregnancy because of HG	123 (15.2%)
Psychological sequelae, for example, depression, anxiety	54 (6.7%)
Any one of the above psychosocial outcomes	669 (82.8%)

a worse area. Husband has had impotence for over 2 years and I was also terrified of sex in case I got pregnant again. Neither of us could consider another pregnancy, so we are trying to adopt to complete our family.

Social isolation, problems relating to other family members and marital problems were frequently mentioned. For several women, these problems resulted in divorce. Typical comments were

- I did not enjoy my pregnancy like other women. I feel I missed out.
- My biggest fear in facing HG again is the loneliness and abandonment I had to deal with. It's like you stop existing.
- I feel like I have failed at being a mom and a wife sometimes.

- There have been plenty of times when my husband has walked into the house and seen me on the couch sobbing with a bucket and just dry heaves, and he has turned around and walked right out of the house. It is very trying when they see us in such agony with no relief.

Most women surveyed (76.0%) reported changes in their plans for future childbearing (Table 2). Many (19.4%) developed a fear of pregnancy, and some specifically developed a fear of having sex. Over one-third (34.8%) changed their mind regarding or considered limiting the number of children they planned to conceive, and several used adoption or surrogacy to reach their family goals. Many increased the spacing of their pregnancies. A substantial number (15.2%) voluntarily terminated at least one pregnancy because of HG. These comments were representative:

- I am terrified to experience another pregnancy.
- I don't think I could survive this again.
- I do not want to be pregnant again. My husband wants another child. This is causing a lot of strain on our marriage.
- We feel we were torn apart by my long hospitalization, and we grieve for the children we will never conceive in the future.
- Will it be fair to the first child for me to willingly get pregnant and risk being so ill and useless again?
- My husband had a vasectomy before I delivered!

Fifty-four women (6.7%) reported serious psychological sequelae from their HG experience (Table 2). These were largely reported as depression, sadness, anxiety and emotional distress. In addition, nightmares, panic attacks, post-traumatic stress disorder and suicidal thoughts were mentioned. Many mentioned that they were in therapy, and some wished that they had started sooner. One woman stated that she ‘spent 18 months under the watchful eye of social services after the birth of my son, as they believed I was mentally ill, that my depression was not caused by HG.’ Another remarked, ‘HG is still affecting me two and a half years later. I used to be very tough. Now I'm fragile.’

Sixty-three women (7.8%) stated that their health-care providers stated or implied that HG was ‘all in their head’ or that they

**Table 3** Reported health-care provider response by country of residence

Characteristic	Australia (N = 43)	Canada (N = 28)	Great Britain (N = 73)	Other (N = 38)	USA (N = 626)	Total (N = 808)	P-value
Patient was told that her HG was psychological or that she was 'faking it'	2 (4.6%)	2 (7.1%)	9 (12.3%)	6 (15.8%)	44 (7.0%)	63 (7.8%)	0.1595
Provider was uncaring or did not understand how sick patient was	12 (27.9%)	6 (21.4%)	30 (41.1%)	15 (39.5%)	169 (27.0%)	232 (28.7%)	0.0550
Patient changed health-care provider	11 (25.6%)	1 (3.6%)	3 (4.1%)	0	84 (13.2%)	99 (12.2%)	0.0006

**Table 4** Relationship of poor provider response (provider was uncaring or did not understand how sick patient was) to select patient outcomes, controlled for severity of HG

Patient outcome	Provider was uncaring or did not understand how sick patient was (OR, 95% CI, P-value)	Severe HG (OR, 95% CI, P-value)	P-value of equation
Patient was told that her HG condition was psychological or that she was 'faking it'	5.024 (2.919–8.648) $P < 0.0001$	1.657 (0.936–2.935) $P = 0.0832$	$< 0.0001$
Psychological sequelae, for example, depression, anxiety	1.864 (1.055–3.293) $P = 0.0319$	0.778 (0.442–1.368) $P = 0.3834$	0.0541
Patient changed health-care provider	1.819 (1.165–2.839) $P = 0.0084$	1.910 (1.182–3.088) $P = 0.0083$	0.0020

Abbreviations: CI, confidence interval; HG, hyperemesis gravidarum; NG, nasogastric; OR, odds ratio.

Severe HG was defined as any one of the following: intravenous hydration, parenteral nutrition, use of NG tube, hospitalization or home infusion therapy.

were 'faking it.' Overall, 28.7% of women reported that their health-care providers were either uncaring or did not understand how sick they were (Table 3). In long narratives, women reported the difficulties they had in getting the attention of their doctors, midwives and nurses, before they could be treated. Several of women's comments regarding their health-care providers' attitude are listed here:

- I was told I should quit pretending to be sick.
- I was told I couldn't be as sick as I was.
- When I called to say that I was vomiting uncontrollably, and had lost 9 pounds in 1 week, she said, 'That is pregnancy—deal with it.'
- I had several doctors yelling at me saying 'stop this at once—you must eat something.'
- I had no medical kindness.
- He did not give any medication until I had lost 25 pounds in 3 weeks.
- I got the feeling that until I fainted and was extremely dehydrated, no one would do a thing.
- My health provider told me that 'My subconscious was rejecting the baby and trying to get my body to dispose of the baby.'
- One psychiatrist I had to see said: 'Do you really think you have all these symptoms?'
- My first OB was extremely uncaring and ridiculed me for my condition. She felt that I was just overreacting to a perfectly normal condition.

In contrast, many women praised their health-care providers and their efforts. A typical response for women who appreciated their providers' efforts was 'My doctors were awesome and supportive. They called in other experts and researched this greatly.' Another stated, 'They were very quick to assure me that this was not my fault, and was from nothing I had done.'

Logistic regression modeling was performed to determine if this 'poor response' was associated with any of the psychosocial outcomes reported, controlling for the reported severity of the HG (Table 4). Women who reported that their health-care provider was uncaring or unaware of the severity of their symptoms were nearly twice as likely to report these psychologic sequelae (odds ratio 1.86, 95% confidence interval 1.06 to 3.29,  $P = 0.032$ ), while overall, severity of HG, as best as could be interpreted from these data, did not appear to be notably related to any of the reported psychosocial outcomes.

However, logistic regression demonstrated that both provider attitude and severity of HG appeared to contribute to a woman's changing her health-care provider (Table 4). Women with HG appeared to change their health-care providers frequently, searching for, and often finding, compassionate and competent help:

- I had to go to 3 different doctors before being taken seriously.
- The first doctors' group was absolutely unsupportive—thought it was all in my head, offered no hope. Wound up terminating as a result. I changed doctors and hospitals and had an extremely supportive network of medical providers. I could

not have asked for better. I had 2 children with their help and support.

- It took me a long time to find a doctor, clinic or office that understood my symptoms, and the serious nature of my emesis. When I found the right doctor, I knew immediately. He took action on the spot and refused to let me suffer even a single day longer.

Women also commented that their treatment usually improved upon subsequent pregnancies, even with the same provider, who now was able to recognize the seriousness of her condition and respond earlier. Women generally noted that early treatment helped mitigate their symptoms, although there did not appear to be a consensus regarding whether symptoms worsened with subsequent pregnancies.

## Discussion

Many unsubstantiated and unlikely theories have proliferated to attribute the origin of HG to a variety of psychosocial conditions, such as a physical manifestation of pregnancy rejection by mother,<sup>3</sup> hysteria<sup>2,18</sup> or conversion disorder.<sup>19</sup> Eating disorders<sup>20</sup> and social factors<sup>21</sup> have also been reported to be associated with HG, and have often been considered as causal. These incorrect and skeptical views of caregivers and family members of affected women can result in a lack of sympathy and suboptimal management of HG patients. Munch<sup>22</sup> stated that a major factor in patient satisfaction was that caregivers understand and appreciate that HG is a disease state that was not caused by the patient herself. Simpson *et al.*<sup>23</sup> substantiated this view in a case–control study, which showed that although women with HG pregnancy scored significantly higher on three scales associated with conversion disorder during their pregnancy, women with and without HG scored equally on these scales during the postpartum period. Our results are consistent with this supposition, that these psychosocial conditions may be the result of HG rather than its cause, in that a poor response from health-care providers was associated with (1) reports of psychologic sequelae, such as depression and anxiety, and (2) reports of women changing providers to seek more compassionate or competent care. Furthermore, many women reported being able to find such care.

Our survey of such a large number of women with HG highlights the negative impact of HG on women's quality of life, with over 80% reporting some negative psychosocial or economic consequence. A new finding was that some of the women surveyed noted that health effects secondary to HG, such as psychologic sequelae, hypersalivation, poor appetite and aversion to certain foods, continued after delivery of the index pregnancy. The long-term impact of HG on the health of women has not been studied and the results of this survey suggest that such a study is needed. Nearly one fifth of these women reported fear of future pregnancies,

and many of these directly stated that they did not want a future pregnancy because of HG. The impact of HG on women's attitude toward future pregnancy may reflect the depth of these negative psychosocial and economic consequences.

Treatment patterns and health-care provider attitudes appeared to vary somewhat by women's country of residence. This may reflect differences in practice patterns and available medications and resources, and perhaps even the prevalence of HG. Evidence for nausea in early pregnancy has been documented in the majority of ethnicities with population frequencies ranging from 35 to 84%.<sup>24</sup> Hospitalization for severe NVP or HG also appears to vary between populations. The estimated incidence of 1 to 2% for hospitalization due to NVP in the United States<sup>1</sup> is in stark contrast to the 10.8% incidence reported in Shanghai, China.<sup>25</sup>

We recognize the limited nature of such an open-ended survey, and that these results are not population-based, but rather are intended to document the diversity and potential severity of life changes among these women. For this reason, we cannot, from these data, estimate the numbers of women affected, nor the economic burden posed by HG. Furthermore, these data are gleaned from self-reports, without confirmation of the diagnosis of HG. Nevertheless, these results are likely to represent those women who were most severely affected because of the individual interest and effort required to locate this survey on the internet. Furthermore, because of the qualitative nature of this survey, most individual conditions are likely to have been under-reported. As we learn more about these severely affected women, who are often cared for within their communities and who may not come to the attention of academicians or perinatologists, we may also achieve more insight regarding NVP, which, although much less severe, continues to affect the majority of pregnant women.

Given that we do not understand why women develop NVP or HG, and that consequently, treatment of women's physical symptoms has had limited success, this condition can evolve into a state in which women are physically exhausted and emotionally overwhelmed. This depletion of physical, mental and emotional resources can profoundly affect multiple aspects of women's lives. When treating these women, caregivers should be aware of the frequency and diversity of the psychosocial aspects of HG. Further research should focus on enabling prenatal care providers to identify women most at risk for these negative psychosocial consequences, so that a comprehensive management plan can be developed and implemented during their pregnancies.

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## Appendix A Survey questions relevant to this study.

1. What was your health provider's attitude toward hyperemesis care and you?
  - (a) Overall very supportive and helpful
  - (b) Eventually realized how sick I was and helped me
  - (c) Did not understand how sick I was
  - (d) Overall not sympathetic or caring
2. What specific treatments were offered for hyperemesis?
3. How has your life or future plans changed after experiencing hyperemesis?