

Original research article

Elective pregnancy termination in a large cohort of women with hyperemesis gravidarum[☆]

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Abstract

Background: This study was conducted to describe characteristics of women who terminated their pregnancies secondary to hyperemesis gravidarum (HG).

Study Design: Data were obtained from a survey provided on an HG Web site from 2003 to 2005.

Results: Of 808 women who completed the survey, 123 (15.2%) had at least one termination due to HG, and 49 (6.1%) had multiple terminations. Prominent reasons given for the terminations were inability to care for the family and self (66.7%), fear that they or their baby could die (51.2%), or that the baby would be abnormal (22.0%). These same women were three times as likely to state that their health care providers were uncaring or did not understand how sick they were [64/123 (52.0%) vs. 168/685 (24.5%), odds ratio 3.34 (95% CI 2.21–5.05), $p < .001$].

Conclusion: These data suggest that the physical and psychological burden of HG has been underestimated, and that further education within the medical community may be warranted.

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1. Introduction

Hyperemesis gravidarum (HG) is a severe manifestation of nausea and vomiting of pregnancy, leading to weight loss during pregnancy [1,2]. HG affects 0.3–2.0% of pregnancies

and can result in dehydration, electrolyte disturbance and nutritional deficiency, in many cases, mandating intravenous hydration and, for some, the use of parenteral nutrition. Severe cases can result in Wernicke's encephalopathy [3], central pontine myelinolysis [4], hepatic dysfunction [5] and renal failure [6]. The diagnosis of HG is also associated with low birth weight, intrauterine growth restriction, preterm delivery, and fetal and neonatal death [7–9]. Treatment is generally supportive, occurring through maintenance of hydration and electrolyte status and management of symptoms [1,2]. However, such supportive care may not be adequate in the most severe forms of HG [10,11].

Cases of elective pregnancy termination due to severe maternal complications of HG have been reported in the literature [12,13]. Nevertheless, the scarcity of information regarding voluntary terminations due to HG has resulted in a general underestimation of the seriousness of this disorder. Formerly, some authors believed that HG was the consequence of an unwanted pregnancy rejection by the mother

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Table 1
Elective pregnancy termination by women's country of residence (p=.340)

| Country | Women reporting at least one elective termination due to HG (n=123) | Women reporting no elective termination due to HG (n=685) |
|------------------------------|---|---|
| United States (n=626) | 90 (14.4%) | 536 (85.6%) |
| United Kingdom (n=73) | 14 (19.2%) | 59 (80.8%) |
| Australia/New Zealand (n=43) | 7 (16.3%) | 36 (83.7%) |
| Canada (n=28) | 5 (17.9%) | 23 (82.1%) |
| Other (n=38) | 7 (18.4%) | 31 (81.6%) |
| Total (N=808) | 123 (15.2%) | 685 (84.8%) |

[14]. However, results of two subsequent cohort studies of nausea and vomiting of pregnancy performed by Mazzotta et al. [13,15], later contested this view. These data suggest that women with nausea and vomiting of pregnancy who underwent elective pregnancy termination compared with those who did not do so were more likely to have reported severe vomiting, feelings of depression, weight loss, family strain, having been undertreated by their health provider and having received a lack of support from their partners.

Here, through the use of a registry for women with HG, we describe a group of women's self-reports regarding the use of elective pregnancy termination as a result of their illness.

2. Materials and methods

The Hyperemesis Education and Research Foundation was created in 2002 as a nonprofit foundation, and as part of its mission, it has created a registry for women with HG and has initiated various online surveys regarding their experiences. The "Treatment and Termination Survey," which was offered from May 2003 through June 2005 was, by its nature, cross-sectional. Women from a variety of countries located the survey through an internet search regarding HG. Structured questions were provided for treatments received, reasons for termination, and provider attitudes, with additional space allowed for narrative comments (Appendix A). HG was defined as significant weight loss and debility secondary to nausea and vomiting during pregnancy, typically requiring medications and/or intravenous fluids for treatment. Elective pregnancy terminations for reasons other than HG were not consistently reported. Health care providers included physicians, midwives and nurses. Themes reported in the comments, such as the impact of HG on family size and career, were explored and categorized.

Women who elected to terminate at least one pregnancy were compared with those who did not, with respect to treatments, provider attitudes and life changes. All analyses were performed at the level of the woman. All data were analyzed by SAS (v. 9.0, Cary, NC). Statistical significance was determined through chi-square testing with

Yates correction, and the relative risk and its 95% CI were calculated where informative. The study was approved through the institutional review board of the University of Southern California Health Sciences Campus.

3. Results

Overall, 808 women from 23 countries participated in the survey, with 77.5% from the United States (Table 1). Women reported having HG up to 13 times, with a median of 2 pregnancies. In the women with HG, gravidity was reported up to range from 1–15 with a median of 2, and parity ranged from 0–8 times with a median of 1. The number of elective pregnancy terminations for other reasons and the number of miscarriages were not documented.

Gestational age at the time of loss was not consistently reported. 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 2 pregnancies, 453 (83.1%) reported at least 1 recurrence of HG.

The number of women reporting at least one elective pregnancy termination because of HG was 123 (15.2%), and of these, 49 (39.8%) reported between 2 and 10 terminations due to HG. An additional 87 women (12.7%) reported that they "almost" terminated their pregnancy due to HG. It was unknown if any of the women participating in the survey did not terminate because such a procedure was not a legal option. The mean age of the women who reported having elective pregnancy termination was slightly older than those women who did not have a termination (mean 30.9±5.0 years, median 31.0, range 19.0–54.0 vs. mean 32.2±5.8 years, median 32.0, range 21.0–54.0, p=.007).

Reasons for termination of pregnancy among these 123 women are listed in Table 2. Treatments, provider attitudes, and the impact of HG are compared for women who did and did not terminate due to HG in Table 3. Comments regarding future pregnancies are documented in Table 4. Some women stated that they adopted or used a surrogate to increase their family size.

Table 2
Reasons for elective termination due to HG. n=123

| Reason | n (%) |
|--|-------------|
| Emotional distress | 74 (60.2%) |
| Fear that the baby would be abnormal | 27 (22.0%) |
| Fear that either she or her baby would die | 63 (51.2%) |
| Did not think HG would recur | 12 (9.8%) |
| No help received from health care provider | 45 (36.6%) |
| No help received from treatments | 31 (25.2%) |
| Unable to care for self or family | 82 (66.7%) |
| Unable to work | 49 (39.8%) |
| No hope for relief | 107 (87.0%) |
| Additional medical concern | 6 (4.9%) |

Women could choose as many reasons as applied.

Table 3

Treatments, provider attitudes, and impact of HG among those who did and did not voluntarily terminate at least one pregnancy due to HG

| Characteristic | Women who voluntarily terminated (n=123) [n (%)] | Women who did not voluntarily terminate (n=685) [n (%)] | Odds ratio and 95% CI | p value |
|--|--|---|-----------------------|---------|
| Treatment | | | | |
| Intravenous hydration | 64 (52.0%) | 400 (58.4%) | 0.77 (0.52–1.16) | .224 |
| Parenteral nutrition | 10 (8.1%) | 91 (13.3%) | 0.58 (0.27–1.19) | .149 |
| Nasogastric tube | 3 (2.4%) | 14 (2.0%) | 1.20 (0.27–4.53) | 1.000 |
| Ondansetron (Zofran) | 50 (40.7%) | 363 (53.0%) | 0.61 (0.40–0.91) | .015 |
| No medications | 13 (10.6%) | 37 (5.4%) | 2.07 (1.01–4.19) | .047 |
| Hospitalization (from comments) | 13 (10.6%) | 70 (10.2%) | 0.78 (0.36–1.61) | 1.000 |
| Home health care (from comments) | 7 (5.7%) | 40 (5.8%) | 0.97 (0.39–2.33) | 1.000 |
| Attitudes | | | | |
| Providers were uncaring or did not realize how sick women were | 64 (52.0%) | 168 (24.5%) | 3.34 (2.21–5.05) | <.001 |
| Impact of HG | | | | |
| Fear of future pregnancy | 30 (24.4%) | 127 (18.6%) | 1.42 (0.88–2.28) | .166 |
| Career problems | 3 (2.4%) | 62 (9.1%) | 0.25 (0.06–0.85) | .021 |
| Inability to care for self or family | 5 (4.1%) | 19 (2.8%) | 1.49 (0.48–4.32) | .625 |
| Marital strain | 6 (4.9%) | 30 (4.4%) | 1.12 (0.41–2.90) | .993 |
| Family strain | 4 (3.3%) | 19 (2.8%) | 1.18 (0.33–3.75) | .642 |
| Financial strain | 4 (3.3%) | 32 (4.7%) | 0.69 (0.20–2.08) | .642 |
| Psychological strain | 10 (8.1%) | 44 (6.4%) | 1.41 (0.65–3.02) | .612 |

Characteristics were classified as positive if reported for at least one pregnancy.

Several themes emerged in the narrative comments provided by the surveyed women. First, providers’ knowledge and attitudes varied tremendously: 94 (17.9%) women voiced positive comments regarding their providers; an additional 25 (4.8%) were positive but stated that they received little help; 107 (20.4%) stated that their providers were unaware of HG and were of no help to them; 78 (14.9%) felt that they had to become extremely ill before they received attention from their providers and 85 (16.2%) mentioned that their care improved upon changing providers. Sixty-three women (7.8%) stated that their providers either told them directly or implied that their condition was psychological.

Another identified theme was that many women with HG had fewer problems in subsequent pregnancies, not only because they knew what to expect but also because they were treated much earlier. Lack of insurance coverage for HG hospitalizations and for medication (ondansetron) (Zofran) was also raised by a number of women. Post termination, some women expressed a lingering depression and anxiety, although nausea was usually reported to disappear quickly. One woman stated that her symptoms were completely resolved upon awakening after her termination.

4. Discussion

Therapeutic pregnancy termination has been addressed in the literature as a “last resort” for treating women with HG with intractable vomiting [1,16]. However, there is now evidence to suggest that the severe psychological and social

consequences of HG, not just the physical symptoms alone, may lead women to consider pregnancy termination. In a study of women with nausea and vomiting of pregnancy by Mazzotta et al. [15], 108 (3.4%) out of 3201 women terminated their pregnancy, which was independently associated with unplanned pregnancy, multiparity, and feelings of depression. In a similar study, women with nausea and vomiting of pregnancy who terminated their pregnancy reported less support from their husbands or partners than those who did not do so [13]. As nausea and vomiting of pregnancy can affect up to 80% of pregnant women, these findings suggest that large numbers

Table 4

Comments mentioned regarding future pregnancies by women who did and did not voluntarily terminate due to HG

| Comment | Yes | Consider | No mention |
|------------------------------------|-------------|------------|-------------|
| Wanted to limit family size | | | |
| Voluntary termination (n=123) | 25 (20.3%) | 10 (8.1%) | 88 (71.5%) |
| No voluntary termination (n=685) | 166 (24.2%) | 80 (11.7%) | 439 (64.1%) |
| p=.9492 | | | |
| Wanted no more pregnancies | | | |
| Voluntary termination (n=123) | 23 (18.7%) | 7 (5.7%) | 93 (74.6%) |
| No voluntary termination (n=685) | 201 (29.3%) | 68 (9.9%) | 416 (60.7%) |
| p=.2593 | | | |
| Performed sterilization | | | |
| Voluntary termination (n=123) | 6 (4.9%) | 5 (4.1%) | 112 (91.1%) |
| No voluntary termination (n=685) | 32 (4.7%) | 4 (0.6%) | 649 (94.7%) |
| p=.1612 | | | |

of women may be seriously affected by its physical and psychosocial consequences.

In this large group of women with HG, 15% reported terminating at least one pregnancy because of this condition. These women who terminated did not appear to have the most severe forms of HG but reported relatively equivalent negative social and physical consequences from their pregnancies. Nevertheless, there is little doubt that symptoms were severe within this group of women with HG, among those who did and did not terminate, given that 19% reported a fear of future pregnancy and 37% either decided or deliberated whether to forego future pregnancies after their HG experience.

What does appear striking is that women who terminated were more likely to report a negative attitude from their caregiver. As treatments and supportive care varied greatly among women, with at least a third reporting that they received little or no help from their health care providers, it is not surprising that most of these women (87%) expressed that one reason for their termination was that they had no hope for relief.

Although not well substantiated, a long-held belief regarding the etiology of HG is that it represents a symbolic rejection of pregnancy [17]. This view still seems to be widely believed by physicians, patients, and their families [13]. Fairweather [14] attributed HG to infantile personality and hysteria, and El-Mallakh et al. [17] explained it, at least partially, as a conversion disorder. Simpson et al. [18] rejected this hypothesis 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, when examined during the postpartum period, women with and without HG scored equally on these scales. They concluded that HG was more likely to be the cause of this conversion disorder and not its effect.

However, this attribution of HG to psychological factors may still be dominant among health care providers and was certainly evident in this study. Such an attitude may encourage a poor physician–patient relationship and, in fact, lead to patient undertreatment. Suboptimal treatment of women with HG may contribute to their decision to terminate their pregnancy. At least half of the women surveyed voiced a difficulty and frustration in receiving attention from their doctors, midwives, and nurses, typically being told that they were not sick, “they were pregnant.” As their complaints were summarily dismissed, many experienced substantial complications, including hematemesis or severe dehydration, before they felt that their problem was recognized to be present. These results suggest an opportunity on the part of the medical profession to increase its awareness of the presentation and potential consequences of HG, so that even without an understanding of its etiology, a prompt and responsive treatment plan can be initiated.

We emphasize that this study’s findings are very preliminary. All data are self-reported, and because women

had to seek out the survey on the Internet and join the HG registry, their experiences may reflect those women with more severe symptoms of HG. A large portion of the data was qualitative and collected through narrative format, so that interpretation of women’s experiences may lack some precision. Furthermore, in addition to the lack of a consistent reporting of other voluntary and spontaneous early pregnancy abortions, and the lack of data from a comparable group of unaffected women, the terminations reported here may not be perceived in their full context.

Nevertheless, this survey of over 800 women with HG documents a serious physical and psychosocial burden that has not been fully recognized by clinicians. Although we do not understand the complexity of women’s decisions to abort their pregnancies associated with HG, we believe that this study suggests some avenues for further exploration regarding how this burden may be mitigated and that further education within the medical community is warranted.

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. How many times have you voluntarily terminated (aborted) due to HG? (excluding miscarriages)
 - a. None, didn’t even consider it
 - b. None, felt too guilty even thinking about it
 - c. Almost did ____ times
 - d. Voluntarily terminated (aborted) ____ times
3. What (if any) other reasons existed to lead you to terminate your pregnancy?
 - a. Baby died due to complications/treatment of HG
 - b. Emotional stress (depression, anxiety, trauma)
 - c. Feared baby would be abnormal due to HG or treatment
 - d. Feared self or baby would die
 - e. HG recurred, was told it would not
 - f. Lack of confidence in medical care of doctor
 - g. Lack of support from family/friends
 - h. No treatments offered
 - i. Non-HG (unplanned, genetic syndrome, etc.)
 - j. Treatments ineffective or not tolerated
 - k. Unable to work, may lose job
 - l. Very sick and miserable, no hope for relief
 - m. Medically necessary — NOT related to HG (please specify reason)
 - n. Other reasons (please specify)
4. How has your life or future plans changed after experiencing hyperemesis? (open-ended)

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