



HER FOUNDATION

HYPEREMESIS EDUCATION & RESEARCH

HER Foundation 2004 Future Research Survey (FRS) Summary of Initial Results

Purpose

In 2004, the HER Foundation conducted an online survey called the **Future Research Survey (FRS)** to identify important trends in the health status and treatment of women with Hyperemesis Gravidarum (HG). This 2004 report is the first of several that will summarize the findings of the **FRS**. The HER Foundation will continue to conduct the FRS survey in 2005 and the updated results will be published at HelpHER.org later this year.

Methodology

Over the course of 2004, 663 women with HG, mostly from the US and the UK, responded online to the **FRS**. Most respondents participated in the survey after visiting the HER Foundation's Web site (HelpHER.org) and seeing the link, learning of the new survey by e-mail announcement, or discussion on the HER Foundation's online forums. Results from other medical research and studies have been included in this summary as background on HG.

Overview of HG

HG is a debilitating and potentially fatal disease of pregnancy with no known cause or cure. The disease is often medically misunderstood, misdiagnosed and mistreated. Women with HG are significantly impacted by this disease, especially if their symptoms are prolonged or severe. HG's physical symptoms are often devastating. Its emotional impact is just as great, and can leave women feeling depressed and alone as they struggle to cope with residual effects ranging from lost jobs and escalating medical bills, to strained personal relationships. Lack of support and inadequate care drive many women to terminate wanted pregnancies and/or reduce family size. Total incidence of HG is unknown, in part to inconsistent diagnosis criteria; however, .05 percent to 2 percent of U.S. pregnant women are hospitalized for HG each year (AGOG, 2004¹). International studies report an incidence of HG as high as 10 percent (Zhang, 1991²; Czeizel, 2003³).

Due to outdated medical literature, HG continues to be erroneously attributed to stress, lack of psychosocial support, a rejection of pregnancy and/or a psychological disorder. While there is no question that the presence of these factors may worsen HG, they are not the cause. There may even be a genetic link to HG, which would further validate the physiological basis for HG. The **FRS** found that 36 percent of HG women responding to the survey had a relative with HG.

Diagnosis

Marked by rapid weight loss, malnutrition, dehydration and severe, unrelenting nausea and vomiting, HG can lead to serious complications for mothers and their unborn children. The **FRS** found nearly one third of the respondents were told by their primary care physician (PCP) that their symptoms were related to psychosocial stress or emotional issues. Although the **FRS** revealed approximately 73 percent of all the respondent's pregnancies were formally diagnosed with the disease, some respondents commented that they only saw the diagnosis on their chart and were never told about the disease. The **FRS** also found 18 percent of women with HG were still being told they had morning sickness, and 40 percent were told HG was the result of normal pregnancy changes. Some women reported not being given a diagnosis or being uninformed about effective treatments for HG; consequently, nearly 20 percent of all pregnancies were reportedly terminated due to the

mother's concern for her health and to end the misery and debilitation. Interestingly, the **FRS** also found 18 percent of women changed doctors due to inadequate care.

In 2002, the Healthcare Cost & Utilization Project (HCUP⁴) reported 40 percent of hospital admissions for HG were coded as mild, 44 percent severe due to metabolic imbalances, and 11 percent as prolonged or occurring late in pregnancy. In reviewing these statistics, some women diagnosed with HG were also noted to have a diagnosis of depression and/or mental disorder. It is unknown if the diagnosing health professionals were attributing HG to mental disorders or vice versa. Mild and prolonged cases were more likely to have additional psychological diagnoses, versus those with more severe cases, suggesting perhaps that only extreme cases are seen as a physiological disorder.

Treatment

Despite available medications to lessen the severity of HG, many women are not offered effective treatment (Kouzi, Am J of Pharm Educ, 2003⁵), (Motherisk, 1998⁶). A finding of great concern in the **FRS** was that 26 percent of HG mothers carrying to term were not offered antiemetic (anti-vomiting) medication. Traditional treatments often effective for morning sickness were not significantly effective for HG; yet, these treatments were repeatedly offered, sometimes to the exclusion of other, more effective treatments (Effectiveness: Seabands 3 percent, herbal medicine 2 percent, homeopathics 6 percent, anti-motion sickness medication 7 percent, acupuncture 11 percent). This suggests that HG requires more aggressive management to treat the severity of symptoms. Antihistamines were effective for 19 percent of HG women surveyed; however, these mothers often were taking other antiemetic medications simultaneously. The **FRS** revealed Zofran was by far the most effective antiemetic with 67 percent of women reporting that the medication effectively decreased their symptoms; however, it was offered to fewer than half of all women. Phenergan, a commonly prescribed medication, was offered to over half of the women with HG; yet, only 26 percent of mothers found it to be effective. IV fluids and bed rest were other treatments reported by HG women in the **FRS** as being most beneficial in easing symptoms.

Table 1: Effectiveness of Antiemetics Prescribed for HG

Antiemetics	% Effective	% Not Effective	Offered	% Not offered
Phenergan	26	57	51	49
Zofran	67	16	45	55
Reglan	10	64	33	67
Antihistamine	19	53	29	71
Anti-motion sickness	7	68	26	74
Compazine	13	56	25	75
Tigan	6	57	12	88
Steroids	26	29	9	91
Thorazine	0	38	8	92
Diclectin	18	28	8	92

** FRS Study (based on 765 term pregnancies, sorted by most common meds offered)

Nutritional Intervention

Another small study of women with HG found the mean dietary intake of most nutrients fell below 50 percent of the recommended dietary allowances and differed significantly from that of women without HG. More than 60 percent of mothers with HG had deficiencies of thiamine, riboflavin, vitamin B6, and vitamin A. Following treatment with MVI (IV multivitamins), mothers in this study reported a cessation of vomiting and improvement in

blood nutrient status (van Stuijvenberg, 1995⁷). Another study found similar results in women given Total Parenteral Nutrition (TPN).

The **FRS** revealed that only 35 percent of women with HG were given vitamins; yet, 62 percent were given IV fluids. The literature on the detriment to a pregnant mother's health from lack of vitamin intake, as well as nutritional deficiencies such as inadequate protein intake is prolific (Mahajan, 2004⁸). For example, vitamin K deficiency, which is not routinely added to TPN, can increase the risk of hemorrhage (Sakai, 2003⁹) and miscarriage. This may contribute to the nearly 30 percent miscarriage rate reported by women in the **FRS**.

It is possible that some women in the **FRS** study did not know they were receiving vitamins; however, it is common for women to be refused MVI for unknown reasons, despite weeks of vomiting and fasting. MVI is inexpensive and can prevent permanent neurological damage or death from conditions such as Wernicke's Encephalopathy. Stores of B vitamins are depleted within 2 weeks of fasting, so it is essential to replace them in women with HG. Further, vitamin B6 has been researched and its stores are often depleted in women suffering from HG. Once B6 was provided, many HG women showed an improvement in their symptoms. Finally, some women have serious complications resulting from the lack of MVI being added to TPN, which should be routine.

HCUP reports 1803 discharges in 2002 for women with HG receiving central venous catheters (CVL). CVLs can be lifesaving in that they offer consistent access to a mother for fluids, medication and nutrition. However, they also pose the risk of clots (emboli) and infection which can result in death. Further, according to HCUP, less than 20 percent of all discharges for CVL placement due to HG were also given Total Parenteral Nutrition (TPN). This is concerning considering the poor nutritional status of women with HG. It could be due to cost, as HCUP reports a mean length of stay (LOS) for women receiving CVL to be about 5.4 days and costing a mean of \$17,500 per admission. Women also given TPN had a mean of 9 days and TPN costs of \$22,912 in addition to hospitalization costs (mean costs). The **FRS** found only 19 percent of mothers with HG (term pregnancies) were offered TPN, while 54 percent reported that TPN was effective in reducing nausea and vomiting.

The **FRS** found the average weight loss for a term HG pregnancy was 15 pounds or 11 percent of a woman's pre-pregnancy body mass. One mother reported a loss of nearly 80 pounds. At least 17 percent of mothers (term pregnancies) lost over 15 percent of their body mass, and 44 percent greater than 10 percent. Considering this significant loss of weight and added oxidative stress at a time when a mother's health is crucial, it is concerning that nutritional therapies are not instituted earlier and more frequently.

Impact

Few truly understand the impact of HG on women and their families. It is often thought of as a self-limiting disorder that ends after a few months without significant adverse effects on the mother and child. However, the recurrence rate among all HG pregnancies in the **FRS** was 87 percent, contrary to recurrence rates of 26 percent to 50 percent reported in medical literature. Further, contrary to popular belief, HG symptoms typically do not subside by the end of the first trimester. In fact, with 1262 respondents, a separate HER Foundation Duration of HG poll found 41 percent had nausea and/or vomiting until after 30 weeks of pregnancy, some until delivery. Similarly, the **FRS** found over 22 percent of women with HG had symptoms throughout pregnancy, and 22 percent of those reported their symptoms remained the same for their entire pregnancy. (Note: The **FRS** asked if women's symptoms remained the same throughout their pregnancy, so those with symptoms throughout may not have answered because their symptoms increased or decreased over time.)

The severity and duration of nausea and vomiting may help explain the nearly 20 percent termination rate among all HG pregnancies reported in the **FRS**. The inadequate intake of food and fluids caused by HG, along with normal pregnancy changes, quickly leads to debilitating fatigue. Most women with HG are unable to maintain employment and/or care for their families during early pregnancy, and some throughout their pregnancy (O'Brien, 1992¹⁰), (Meighan, 2005¹¹). Some are even unable to care for themselves. By far, the majority of women in the **FRS** reported a period of weeks if not months of total bed rest out of necessity. Recovery after HG is also longer than the average 6-8 weeks experienced by non-HG mothers after delivery. Women in the **FRS** reported an average of nearly 4 months for recovery, and 13 percent required more than a year.

Further, despite the commonly held belief that HG presents an insignificant risk to most mothers and babies, the **FRS** found HG women surveyed were twice as likely to miscarry and experience preterm labor as non-HG women. Recent publications also find HG increases the risk of premature delivery and a low-birth-weight

neonate (Paauw, 2005¹²), as well as prenatal and postnatal complications (American College of Preventive Medicine, 2005¹³). Other medical research suggests that infants born to mothers with HG have an increased risk of significant cognitive and behavioral disorders, as well as chronic illness in later life due to maternal malnutrition (McMillen, 2005¹⁴) and stress (Van den Bergh, 2005¹⁵). Although no long-term health study has been done to date, the **FRS** did find that the greater the weight loss in the mother, the greater the incidence of adverse outcomes in the neonate.

Conclusion

These initial results of the **FRS** provide startling insight into the extent of inadequate care and ineffective treatment often received by HG women. The most concerning result being that more than 20 percent of women with HG were not given any antiemetic medications. Currently, fewer than half of all women are receiving the most effective medication offered for HG treatment, likely due to cost. Nutritional support is offered to few women, despite dramatic weight loss and known nutritional depletion experienced by HG mothers. Considering the enormous research and focus on nutrition during pregnancy, it is concerning that these women are given little if any nutritional therapy during pregnancy. Together these impacts result in terminations of wanted pregnancies and force 75 percent of families to limit family size to avoid recurrent episodes of HG.

The HER Foundation hopes these results will offer health professionals, researchers, and insurers a clearer perspective on effective care and the potential adverse effects of HG. In time, the HER Foundation, in collaboration with consulting health professionals, hopes to standardize the care of HG women with the establishment of an HG treatment protocol.

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